

Northern Ireland Rare Disease Partnership

Northern Ireland · Charity number 105261

Details

Known as	NIRDP
Status	Received
Company number	611153
Registered	2016-05-17
Register	View on the Charity Commission for Northern Ireland register

Contact

Address C/O Guardian Chartered Accountants
2 William Street
Newtownards
BT23 4ah
BT23 4AH

Phone 07704476929

Email info@nirdp.org.uk

Website www.nirdp.org.uk

Activities

Purposes: OBJECTS (4) The company's objects (Objects) are specifically restricted to the following: (a) to support and campaign on behalf of those persons in Northern Ireland ('the area of benefit') affected by or believed to be affected by a rare disease and their families, dependants, and carers; (b) to advance the education of the public and of relevant professionals and policy makers in all matters concerning rare conditions; and (c) to advance any other exclusively charitable purpose as the directors may, from time to time, decide in accordance with the law of charity

What the charity does: The advancement of education, The advancement of health or the saving of lives, The relief of those in need by reason of youth, age, ill-health, disability, financial hardship or other disadvantage

How the charity works: Advice/advocacy/information, Counselling/support, Cross-border/cross-community, Disability, Education/training, General charitable purposes, Medical/health/sickness, Volunteer development

Who the charity helps: Adult training, Carers, Children (5-13 year olds), General public, Learning disabilities, Men, Mental health, Parents, Physical disabilities, Preschool (0-5 year olds), Sensory disabilities, Voluntary and community sector, Volunteers, Women, Youth (14-25 year olds)

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£29,649	£61,336	£0	2

Trustees

Name	Role	Appointed
Aj Mcknight		
Anne Marie O'loan		
Caoimhe Mckenna		
Christine Collins		
Dr Nazia Chaudhuri		
Eva Fox		
Fiona Mclaughlin		
Samuel Robinson		
Sandra Campbell		

Northern Ireland Rare Disease Partnership

Northern Ireland - Charity number 105261

Accounts

Our Ref: PA/CJ
Date: 6 February 2026
Code: PM1015

The Trustees
Northern Ireland Rare Disease Partnership
Guardian Chartered Accountants
2 William Street
Newtownards
BT23 4AH

Dear Fiona & Anne Marie

Please find attached PDF of the following document that requires your electronic signatures.

1. Accounts for the year ended 31 March 2025.

Yours sincerely

Paula Armstrong

[Paula Armstrong \(Feb 6, 2026 11:07:05 GMT\)](#)

Mrs Paula Armstrong
On behalf of MTS Chartered Accountants

Enc

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Registered to carry out audit work by the
Institute of Chartered Accountants in Ireland



Registered with The Chartered Institute of
Taxation as a firm of Chartered Tax Advisors

www.mtsaccountants.com – A full list of Directors of
McCreery Turkington Stockman Ltd is available at our website.

N.I. Registration No. NI626535.
MTS Chartered Accountants & MTS Prior McMahan
are trading names of McCreery Turkington Stockman Ltd.

Company registration number NI611153

**NORTHERN IRELAND RARE DISEASE PARTNERSHIP
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025**

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	A O'Loan C McKenna Dr N Chaudhuri S Campbell (Appointed 1 January 2025) C Collins (Appointed 1 January 2025) A J McKnight (Appointed 1 January 2025) F McLaughlin (Appointed 1 January 2025) S Robinson (Appointed 1 January 2025) Eva Fox (Appointed 9 October 2025)
Charity number	105261
Company number	NI611153
Registered office	Guardian Chartered Accountants 2 William Street Newtownards BT23 4AH
Independent examiner	MTS Prior McMahon c/o Ards Business Hub Sketrick House Jubilee Road Newtownards Co Down BT23 4YH

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

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NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

FOR THE YEAR ENDED 31 MARCH 2025

The trustees present their annual report and financial statements for the year ended 31 March 2025.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's Memorandum and Articles of association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (effective 1 January 2019).

Objectives and activities

There are 3 key objectives of the charity, as defined in the governing document, and they are:

1. To support and campaign on behalf of those persons in Northern Ireland ("the area of benefit") affected by or believed to be affected by a rare disease and their families, dependents, and carers.
2. To advance the education of the public and of relevant professionals and policy makers in all matters concerning rare diseases.
3. To advance any other exclusively charitable purpose as the trustees may, from time to time, decide in accordance with the law of charity.

NIRDP are committed to working constructively in partnership with others in the belief that we are stronger together and that we can make a real difference to the lives of people living with rare disease.

We **connect**: bringing together individuals, families, carers and professionals

We **advocate**: campaigning for better recognition and services

We **raise awareness**: educating the public, professionals and policy makers

We **innovate**: finding new ways to improve lives

Public benefit

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake. The Trustees believe that the charitable organisation provides a public benefit in a number of ways through the undertaking of a range of projects and by providing support to all persons affected by a rare disease including individuals, families, dependents and carers. The direct benefit that will flow from this benefit will be to improve the diagnosis, treatment, and support of individuals affected by rare diseases.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

Achievements and performance

Significant activities and achievements against objectives

The trustees are delighted to share the progress and achievements of the charity below.

The Rare Support Hub – Strengthening Support Across Northern Ireland

The NIRDP Rare Support Hub has provided practical and emotional support to children, families, adults, and healthcare professionals across Northern Ireland. Key areas of assistance have included:

- Providing accurate, condition-specific information on rare diseases.
- Signposting to appropriate medical, psychological, and financial support services.
- Facilitating peer connections between people living with similar rare conditions.
- Supporting individuals to navigate diagnosis and treatment pathways.
- Addressing barriers to service access.

Through this work, many families have successfully secured appropriate benefits, approached Benefits Tribunals with greater confidence, and re-engaged with daily life after periods of significant loss of identity and wellbeing.

Over recent months, the Support Hub has expanded its remit, becoming a broader, more integrated service for people navigating the challenges of rare conditions, including the complexities of diagnostic odysseys and postcode variations in care provision. Advocacy remains a core element, with the Hub liaising between clinicians, consultants, and other healthcare professionals, as well as engaging MLAs through the Rare Disease All-Party Group, to ensure policy and service design reflect the needs of the rare disease community.

Core Functions of the Rare Support Hub

- Delivery of in-person and online peer support groups in local communities.
- Peer mentoring based on lived experience.
- One-to-one tailored casework.
- Advocacy for individuals and support for carers.
- Signposting to specialist organisations and local resources.
- Participation in multi-disciplinary teams to integrate health, social care, education, and community responses.

The Rare Support Hub prioritises a “listening first” approach, ensuring interventions are person-centred and responsive. This model not only improves individual wellbeing but also builds community capacity and informs systemic change for the estimated 1 in 17 people in Northern Ireland living with a rare disease.

Support Group Working

Foyle Region

Participants enjoyed an engaging and uplifting programme led by **Janice Tracey, nutritionist** and **Mandy Chism, Assistant Director, Facilitator, and Master Trainer at Resilio**. Both speakers brought a wealth of knowledge and practical advice, sharing strategies to support better mental health and overall well-being.

In collaboration with the Northwest-based charity **Resilio**, we hosted a *Resilience and Hope* session that resonated deeply with everyone in attendance. The feedback was overwhelmingly positive, with 100% of both patients and carers saying they left feeling inspired and motivated to incorporate the lessons and tips into their daily lives. The event not only provided valuable tools for coping and thriving but also strengthened the sense of connection and mutual support within our community.

Awards:

Celebrating Outstanding Care – Caring Award Recipient We are delighted to share the story of **Judith Hamilton**, who recently received the *Caring Award* in recognition of her exceptional dedication and compassion. Judith was nominated by her sister-in-law, Catherine, for the unwavering care she provides to her mother, Elsie, who is living with PSP.

The award was presented by **Sandra Campbell** trustee of the Northern Ireland Rare Disease Partnership, in a touching ceremony surrounded by Judith’s family. Catherine’s nomination highlighted Judith’s tireless commitment, kindness, and the difference she makes in her mother’s quality of life each day.

This celebration of Judith’s work serves as a reminder of the vital role carers play in supporting loved ones with rare conditions. We extend our heartfelt congratulations to Judith on this well-deserved recognition.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

Online-Chat Rare

Summary of Online Chat Session – December 2024

One of our December chat sessions was held online with six participants, including individuals and families. During this session, we focused on self-care and discussed ways to strengthen ourselves by doing things we enjoy.

We emphasised the importance of being kind to ourselves and to others. Self-care is essential for everyone, but it is especially important for people living with rare diseases. Taking time for self-care can help manage a condition and improve quality of life.

We encouraged participants to try at least one self-care tip and highlighted that these practices can also benefit carers, helping them to relax and avoid feeling overwhelmed.

Understanding Rare project 2024

The "Understanding Rare" project was a mental health initiative run by the Northern Ireland Rare Disease Partnership (NIRDP) with funding from the Community Foundation's Mental Health Fund. Its purpose was to improve awareness, empathy, and professional skills in supporting people with rare diseases, a community of about 110,000 in Northern Ireland.

Core Activities and Impact Workshops brought together healthcare professionals, support workers, educators, and policymakers to deepen their understanding of rare diseases and the related mental health challenges.

The cascade effect—trained participants applied and shared their new knowledge in their own sectors—amplified the impact well beyond the original target audience.

Professionals became more adept at offering tailored mental health support, improving diagnosis pathways, and advocating effectively for patients and families.

The program directly benefited 60 people and indirectly improved the environment for the broader rare disease community with sectors such as housing, benefits, and social support. These sessions explored the unique mental health challenges that individuals with rare conditions may face at different stages of diagnosis and treatment. Real-life stories from the rare disease community added depth and emotional resonance, helping participants connect professional knowledge with lived experience.

Case Study 1: Healthcare Professional Gaining New Insights: A healthcare professional with over 15 years of experience attended the "Understanding Rare" workshop, initially seeking to broaden their knowledge of rare diseases. Although they had extensive experience in general healthcare, they admitted to having limited understanding of the unique challenges faced by rare disease patients. During the session, they were particularly struck by the stories shared by patients, especially the emotional and mental health struggles that often accompany these conditions. This new perspective profoundly influenced their approach to patient care. After the workshop, the participant said they would incorporate this newfound empathy into their practice, making more time to listen to patients' concerns and being more proactive in seeking out specialist resources for those with rare conditions. They reported that this shift would not only improve their patient interactions but also make them feel more fulfilled in their role, knowing they were offering more comprehensive and compassionate care.

Case Study 2: Parent Advocate Finding Empowerment: A parent of two children with a rare genetic condition attended the workshop, feeling isolated and overwhelmed by the daily challenges of managing their children's needs. The workshop provided them with not only critical information about rare diseases but also a sense of community and support. For the first time, the parent felt empowered to share their story with others who truly understood their struggles, especially after viewing our Rare Stories videos (available on our website www.nirdp.org.uk) and examples of advocate parents. This newfound session has been a lifeline, offering practical advice and emotional support. The parent reported feeling a renewed sense of strength and determination to advocate for their children's needs. They also expressed a desire to become more involved in raising awareness about rare diseases, hoping to help other families avoid the isolation they have felt.

Case Study 3: Newly Diagnosed Patient Finding Hope: A recently diagnosed rare disease patient attended the "Understanding Rare" workshop, seeking information and support. They had spent years experiencing unexplained symptoms and had only just received a correct diagnosis, leaving them feeling anxious and uncertain about the future. During the workshop, the patient was able to connect with others who had similar experiences (especially through our Rare Stories video content available on our website www.nirdp.org.uk), which was both reassuring and empowering. The patient shared their story for the first time in a safe and supportive environment, which helped them process the emotional impact of their diagnosis. After the workshop, they reported feeling less alone and more hopeful about managing their condition. They also expressed appreciation for the practical advice and resources provided, which gave them a clearer path forward. The patient now feels better equipped to navigate their healthcare journey and is motivated to continue learning and advocating for themselves and others in the rare disease community.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

Strengthening Support in Schools: Working with the Education Authority

The Education Action Team, led by **Stephanie Duguez** (Senior Lecturer, School of Medicine, Ulster University) with volunteers **Sandra Campbell** and **Robbie Crouch**, recently met with the Special Educational Needs (SEN) lead at the Education Authority to explore ways of improving support for children and young people with rare conditions in Northern Ireland schools. As part of this work, Sandra and Stephanie conducted an anonymous education survey, gathering valuable feedback from parents and guardians about their experiences of the education system. The results and views shared by parents are documented in our *Rare Disease Education Toolkit*, which is freely available on our website www.nirdp.org.uk. These findings were also presented to the Education Authority and have helped shape ongoing collaboration, which includes delivering awareness sessions for school staff, providing practical tools through the Toolkit, hosting listening sessions with families, and offering signposting to supportive resources. NIRDp is now also listed as a useful resource for medical needs on the Education Authority's website, increasing visibility and access to our support services.

Rare Disease Day, Stormont, 26th February 2025

The Northern Ireland Rare Disease Partnership, Queen's University Belfast, Ulster University, Rare Diseases Ireland, and the Departments of Health in Northern Ireland and the Republic of Ireland convened a noteworthy event to celebrate Rare Disease Day as an all-Ireland group. The program included a welcome and an introduction by Fiona McLaughlin (Co-Chair NIRDp), setting the stage for discussions on advancements and strategic planning in the field of rare diseases. Videos from Mike Nesbitt, Minister of Health in Northern Ireland, and Minister for Health Jennifer Carroll MacNeill wished everyone a happy Rare Disease Day while supporting the group on this day. This was followed by in-depth presentations on the Northern Ireland Rare Disease Action Plan by Finola McGrady and the National Strategy for Rare Disease in the Republic of Ireland by Keith Lyons. The panel discussion, titled 'More than you can imagine: The power of connection and resilience,' was facilitated by Prof AJ McKnight and Dr Suja Somanadhan and featured Rosaline Callaghan, Dr Carleen Walsh, Dr Claire Hill, Melissa Kinch, and Dr Atif Awan, providing diverse perspectives and insights into the strengths and challenges within the rare disease community as parents, patients, carers, and researchers. Christine Collins MBE (Co-Chair NIRDp) provided closing remarks. The event underscored the importance of collaboration, strategic action, the resilience of individuals and families affected by rare diseases, and the spirit of unity in marking Rare Disease Day across the island.

Power of Connection Events, February to April, 2025

We successfully concluded our series of engagement events across Northern Ireland, (Bangor; Derry/Londonderry; Armagh; Belfast; Online) focused on shaping the NI Rare Disease Action Plan. These events, each focused on particular aspects of the Action Plan, facilitated vital conversations, shared powerful patient stories, and gathered crucial feedback from patients, carers, family members, academics/researchers/students, health professionals, policymakers (civil service/elected representatives), industry representatives, allied health professionals, and other community organisations in Northern Ireland working with people with rare diseases. A sincere thank you to the Department of Health, Queen's University Belfast, Ulster University, UCD Dublin, Rare Diseases Ireland, and all other organisations participating. The events were all well supported (even maxing out room capacity) highlighting the strong public support for improving rare disease services across Northern Ireland. Each event included a facilitated workshop using a Think-Pair-Share format to allow common themes and potential solutions to emerge. Emerging Findings are below.

We're preparing a report for the Health Minister to inform the next iteration of the Action Plan, alongside taking forward key findings, such as the importance of peer support and local community connections through intensifying our work at a local level. Some of the issues coming up and being shared at the events are detailed below.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

Storytelling at Power of Connection events

Mr. A told of the journey to diagnosis for his son, which took 7 years from birth. During this time the family had no information and no support. They experienced isolation and bewilderment. This was his first rare disease event.

Ms. B talked about her experience during and after her husband's illness. He had been in hospital in Belfast, needing input from specialists in Edinburgh. He was able to go home only because Ms. B was a nurse and could manage his nasal feeding. Despite paid carers and district nurses visiting, Ms. B had to always be with him because of the risk of his involuntary movements pulling out the feeding tube. Despite his condition being progressive, the care package was reduced. There was no other support available.

Ms. C and her son **Mr. C** described their experiences of living with his rare condition, which has significant impact on his day-to-day life. Last year he took part in a clinical trial based in Belgium, resulting in a 3-month period where he could behave like his friends and experience a "normal" teenage life. The effect of the treatment wore off and his life is more limited again. As a UK resident he doesn't have access to that treatment any longer.

Ms. D spoke of the challenges of living remotely with an ill baby in tertiary care. She told of the impact of city rents and long travel, as well as being removed from family and local support networks.

Corporate Council

We continue to collaborate with our Corporate Council partners for a second year in a row. We are delighted and are incredibly grateful to have the support of industry and thank our Corporate Council members for their engagement and support.

All Party Group for Rare Disease

We have continued to hold the secretariat position for the All Party Group (APG) for Rare Disease at Stormont. There have been a number of meetings over the period with elected MLA's and input from patients, carers and stakeholders to raise awareness of rare disease and ask questions of our elected representatives. We want to thank the APG members for their time and membership, in particular, the Chair, Mark H Durkan, and look forward to continuing this into next year.

The trustees would like to thank the NIRDP team and volunteers for their continued support and efforts in upholding our key aim, which is to ensure that no one in Northern Ireland is disadvantaged due to the rarity of their health condition.

We also would like to thank our funders as follows;

ARN Foundation

The Community Foundation NI

The Department of Health

Our Corporate Council Partners

Our various private donors

Financial review

The financial results for the year are set out on pages 9- 17.

The charitable company generated a deficit for the year of £31,717 (2024: surplus £12,920), which included a deficit of unrestricted funds of £7,492 (2024: deficit £2,515) and a deficit of restricted funds of £24,225 (2024: surplus £15,435).

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

Reserves policy

The charitable company's ongoing reserves policy is to maintain a minimum level of reserves which matches the needs of the organisation both at the current time and in the foreseeable future. The trustees will strive to maintain reserves in the future, sufficient to meet statutory obligations, committed expenditure, core salaries and running costs equivalent to between three and six month's expenditure. The trustees consider that reserves at this level will ensure that, in the event of a significant drop in funding, they will be able to continue the charity's current activities while consideration is given to ways in which additional funds may be raised. This level of reserves has been maintained throughout the year.

Major risks

The trustees have a risk management strategy in place whereby major risks, to which the charity is exposed have been assessed, and Trustees are satisfied that systems are in place to mitigate exposure to the major risks. The risk management strategy comprises:

- an annual review of the risks the charity may face,
- the establishment of systems and procedures to mitigate those risks identified,
- financial risk is managed by the establishment of a reserves policy and its regular review by Trustees,
- attention is also focussed where necessary on the Protection of Children and Vulnerable Adults and Health & Safety in the workplace.

Structure, governance and management

The charity is a company limited by guarantee governed by its Memorandum and Articles of Association dated 22nd March 2021. The Northern Ireland Rare Disease Partnership (NIRDP) is a registered charity with the Charity Commission for Northern Ireland, Number 105261. In the event of the company being wound up members are required to contribute an amount not exceeding £1.

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

C Donnelly	(Resigned 1 June 2024)
S Callaghan	(Resigned 20 December 2024)
A O'Loan	
J Wright	(Resigned 1 May 2024)
J McEvoy	(Resigned 31 August 2025)
C McKenna	
Dr N Chaudhuri	
S Campbell	(Appointed 1 January 2025)
C Collins	(Appointed 1 January 2025)
A J McKnight	(Appointed 1 January 2025)
F McLaughlin	(Appointed 1 January 2025)
S Robinson	(Appointed 1 January 2025)
Eva Fox	(Appointed 9 October 2025)

Recruitment and appointment of trustees

The recruitment procedures for new Trustees are laid out in the NIRDP's Memorandum and Articles of Association. New trustees are recruited based on the relevance of their professional skills and their potential to be able to make a helpful contribution to the governance of NIRDP. As part of the recruitment process they are made aware of a Trustee's legal obligations under charity and company law, the content of the Memorandum and Articles of Association, the charity's decision-making processes, the Strategic Plan and recent financial performance of the charity.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

Organisational structure

NIRDP has a Board of 8 Trustees, who meet at least quarterly and are responsible for the strategic direction and running of the charity. There are 2 individuals engaged by the charity's trustees to assist in delivering the objectives of the charity and to assist in the management of day-to-day operations of the charity and they are supported by a number of volunteers who have been specifically trained to provide that support.

The trustees' report was approved by the Board of Trustees.

Anne Marie OLoan

[Anne Marie OLoan \(Feb 6, 2026 11:51:53 GMT\)](#)

A O'Loan
Director

6 February 2026

Fiona McLaughlin

[Fiona McLaughlin \(Feb 6, 2026 12:40:39 GMT\)](#)

F McLaughlin
Director

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF NORTHERN IRELAND RARE DISEASE PARTNERSHIP

I report on the financial statements of the charity for the year ended 31 March 2025, which are set out on pages 9 to 17.

Responsibilities and basis of report

As the trustees of the charity (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 (the 2006 Act).

Having satisfied myself that the charity is not subject to audit under company law, and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 65 of the Charities Act
- follow the procedures laid down in the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act
- state whether particular matters have come to my attention.

Independent examiner's statement

I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in accordance with the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act. The examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1 accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of section 396 of the Companies Act 2006 other than any requirement that the financial statements give a true and fair view, which is not a matter considered as part of an independent examination; or
- 4 the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the financial statements to be reached.

Paula Armstrong

[Paula Armstrong \(Feb 6, 2026 12:42:06 GMT\)](#)

Paula Armstrong

For and on behalf of MTS Prior McMahon

Chartered Accountants
c/o Ards Business Hub
Sketrick House
Jubilee Road
Newtownards
Co Down
BT23 4YH

Dated: 6 February 2026

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2025

	Notes	Unrestricted funds 2025 £	Restricted funds 2025 £	Total 2025 £	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £
Income from:							
Donations and membership fees	2	19,649	10,000	29,649	9,700	52,000	61,700
Total income		19,649	10,000	29,649	9,700	52,000	61,700
Expenditure on:							
Charitable activities	3	26,712	34,225	60,937	12,215	36,565	48,780
Other expenditure	7	429	-	429	-	-	-
Total expenditure		27,141	34,225	61,366	12,215	36,565	48,780
Net income/(expenditure) and movement in funds		(7,492)	(24,225)	(31,717)	(2,515)	15,435	12,920
Reconciliation of funds:							
Fund balances at 1 April 2024		16,757	28,163	44,920	19,272	12,728	32,000
Fund balances at 31 March 2025		9,265	3,938	13,203	16,757	28,163	44,920

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

BALANCE SHEET

AS AT 31 MARCH 2025

	Notes	2025		2024	
		£	£	£	£
Fixed assets					
Tangible assets	8		1,085		1,546
Current assets					
Debtors	9	9,093		10,000	
Cash at bank and in hand		6,892		34,966	
		<u>15,985</u>		<u>44,966</u>	
Creditors: amounts falling due within one year	10	<u>(3,867)</u>		<u>(1,592)</u>	
Net current assets			12,118		43,374
Total assets less current liabilities			<u>13,203</u>		<u>44,920</u>
The funds of the charity					
Restricted income funds	12		3,938		28,163
Unrestricted funds	13		9,265		16,757
			<u>13,203</u>		<u>44,920</u>

The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 March 2025.

The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the trustees on 6 February 2026

Anne Marie OLoan

[Anne Marie OLoan \(Feb 6, 2026 11:51:53 GMT\)](#)

A O'Loan

Director

Fiona McLaughlin

[Fiona McLaughlin \(Feb 6, 2026 12:40:39 GMT\)](#)

F McLaughlin

Director

Company registration number NI611153 (Northern Ireland)

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2025

1 Accounting policies

Charity information

Northern Ireland Rare Disease Partnership is a private company limited by guarantee incorporated in Northern Ireland. The registered office is Guardian Chartered Accountants, 2 William Street, Newtownards, BT23 4AH.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's articles of association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2016). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors or grantors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

1.5 Resources expended

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

1 Accounting policies

(Continued)

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates;

- Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

- Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the independent examination fees and costs linked to the strategic management of the charity.

All costs are allocated between the expenditure categories of the SOFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, others are apportioned on an appropriate basis.

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	25% reducing balance
-----------------------	----------------------

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

1.7 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.8 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.9 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

1 Accounting policies

(Continued)

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.10 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

1.11 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

2 Donations and legacies

	Unrestricted funds	Restricted funds	Total	Total
	2025	2025	2025	2024
	£	£	£	£
Donations and gifts	2,149	-	2,149	2,186
Grants	-	10,000	10,000	56,014
Membership fees	17,500	-	17,500	3,500
	<u>19,649</u>	<u>10,000</u>	<u>29,649</u>	<u>61,700</u>
For the year ended 31 March 2024	<u>9,700</u>	<u>52,000</u>		<u>61,700</u>
Donations and gifts				
Other	2,149	-	2,149	2,186
	<u>2,149</u>	<u>-</u>	<u>2,149</u>	<u>2,186</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

3 Charitable activities

	2025 £	2024 £
Staff costs	32,044	35,809
Staff and board training	288	-
Forum costs and room hire	1,310	-
Subscriptions	648	115
Insurance	96	96
Printing, postage and stationery	498	-
Telephone	72	88
Computer and internet costs	1,773	2,188
Motor and travel expenses	2,574	659
Consultancy	14,020	7,501
Event expenses	5,223	41
General expenses	568	823
	<u>59,114</u>	<u>47,320</u>
Share of governance costs (see note 4)	1,823	1,460
	<u>60,937</u>	<u>48,780</u>
Analysis by fund		
Unrestricted funds	26,712	12,215
Restricted funds	34,225	36,565
	<u>60,937</u>	<u>48,780</u>

4 Governance costs

	Restricted £	Unrestricted £	2025 £	2024 £
Professional Services	-	1,350	1,350	887
Bank charges	-	112	112	58
Depreciation	-	361	361	515
	<u>-</u>	<u>1,823</u>	<u>1,823</u>	<u>1,460</u>

5 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

6 Employees

The average monthly number of employees during the year was:

	2025	2024
	Number	Number
	2	3
	<u> </u>	<u> </u>
Employment costs	2025	2024
	£	£
Wages and salaries	30,654	35,211
Other pension costs	1,390	598
	<u> </u>	<u> </u>
	<u>32,044</u>	<u>35,809</u>

There were no employees whose annual remuneration was more than £60,000.

7 Other

	Unrestricted	Total
	funds	
	2025	2024
		£
Net loss on disposal of tangible fixed assets	429	-
	<u>429</u>	<u>-</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2025

8 Tangible fixed assets

	Fixtures and fittings £
Cost	
At 1 April 2024	4,857
Additions	329
Disposals	(1,680)
	<hr/>
At 31 March 2025	3,506
	<hr/>
Depreciation and impairment	
At 1 April 2024	3,311
Depreciation charged in the year	361
Eliminated in respect of disposals	(1,251)
	<hr/>
At 31 March 2025	2,421
	<hr/>
Carrying amount	
At 31 March 2025	1,085
	<hr/> <hr/>
At 31 March 2024	1,546
	<hr/> <hr/>

9 Debtors

	2025 £	2024 £
Amounts falling due within one year:		
Trade debtors	-	10,000
Other debtors	3,693	-
Prepayments and accrued income	5,400	-
	<hr/>	<hr/>
	9,093	10,000
	<hr/> <hr/>	<hr/> <hr/>

10 Creditors: amounts falling due within one year

	2025 £	2024 £
Other taxation and social security	-	387
Accruals and deferred income	3,867	1,205
	<hr/>	<hr/>
	3,867	1,592
	<hr/> <hr/>	<hr/> <hr/>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2025

11 Retirement benefit schemes

	2025	2024
	£	£
Defined contribution schemes		
Charge to profit or loss in respect of defined contribution schemes	1,390	598
	<u>1,390</u>	<u>598</u>

The charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the charity in an independently administered fund.

12 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 1 April 2024	Incoming resources	Resources expended	At 31 March 2025
	£	£	£	£
	28,163	10,000	(34,225)	3,938
	<u>28,163</u>	<u>10,000</u>	<u>(34,225)</u>	<u>3,938</u>
Previous year:				
	At 1 April 2023	Incoming resources	Resources expended	At 31 March 2024
	£	£	£	£
	12,728	52,000	(36,565)	28,163
	<u>12,728</u>	<u>52,000</u>	<u>(36,565)</u>	<u>28,163</u>

13 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 April 2024	Incoming resources	Resources expended	At 31 March 2025
	£	£	£	£
General funds	16,757	19,649	(27,141)	9,265
	<u>16,757</u>	<u>19,649</u>	<u>(27,141)</u>	<u>9,265</u>
Previous year:				
	At 1 April 2023	Incoming resources	Resources expended	At 31 March 2024
	£	£	£	£
General funds	19,272	9,700	(12,215)	16,757
	<u>19,272</u>	<u>9,700</u>	<u>(12,215)</u>	<u>16,757</u>

14 Related party transactions

There were no disclosable related party transactions during the year (2024 - none).

Northern Ireland Rare Disease Partnership

Northern Ireland - Charity number 105261

Accounts

Our Ref: PA/JS
Date: 23 December 2024
Code: PM1015
ID: 189527

The Trustees
Northern Ireland Rare Disease Partnership
Guardian Chartered Accountants
2 William Street
Newtownards
BT23 4AH

Dear Sarah & Anne Marie

Please find attached PDF of the following document that requires your electronic signatures.

1. Accounts for the year ended 31 March 2024.

Yours sincerely


[Paula Armstrong \(Dec 23, 2024 09:52 GMT\)](#)

Mrs Paula Armstrong
On behalf of MTS Chartered Accountants

Enc

MTS Chartered Accountants
1 Lanyon Quay
Belfast
BT1 3LG
T +44 (0)28 9032 3040
E info@mtsaccountants.com

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Registered to carry out audit work by the
Institute of Chartered Accountants in Ireland



Registered with The Chartered Institute of
Taxation as a firm of Chartered Tax Advisors

www.mtsaccountants.com – A full list of Directors of
McCreery Turkington Stockman Ltd is available at our website.

N.I. Registration No. NI626535.
MTS Chartered Accountants & MTS Prior McMahon
are trading names of McCreery Turkington Stockman Ltd.

Charity registration number 105261

Company registration number NI611153 (Northern Ireland)

NORTHERN IRELAND RARE DISEASE PARTNERSHIP
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	S Callaghan A O'Loan J McEvoy C McKenna Dr N Chaudhuri
Charity number	105261
Company number	NI611153
Registered office	Guardian Chartered Accountants 2 William Street Newtownards BT23 4AH
Independent examiner	MTS Prior McMahon 104-108 Frances Street Newtownards Down BT23 7DY

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

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Statement of financial activities	6
Balance sheet	7
Notes to the financial statements	8 - 14

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

FOR THE YEAR ENDED 31 MARCH 2024

The trustees present their annual report and financial statements for the year ended 31 March 2024.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's Memorandum and Articles of association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (effective 1 January 2019).

Objectives and activities

There are 3 key objectives of the charity, as defined in the governing document, and they are:

1. To support and campaign on behalf of those persons in Northern Ireland ("the area of benefit") affected by or believed to be affected by a rare disease and their families, dependents, and carers.
2. To advance the education of the public and of relevant professionals and policy makers in all matters concerning rare diseases.
3. To advance any other exclusively charitable purpose as the trustees may, from time to time, decide in accordance with the law of charity.

Public benefit

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake. The Trustees believe that the charitable organisation provides a public benefit in a number of ways through the undertaking of a range of projects and by providing support to all persons affected by a rare disease including individuals, families, dependents and carers. The direct benefit that will flow from this benefit will be to improve the diagnosis, treatment, and support of individuals affected by rare diseases.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

Achievements and performance

Significant activities and achievements against objectives

The trustees are delighted to share the progress and achievements of the charity below.

Virtual Support Hub

Our support hub continues to be a vital source of information and support for the rare disease community in NI. Over 100 people have contacted the team for advice, guidance and practical help in areas including, benefits, health service navigation, access to condition specific information and wellbeing/mental health support and signposting. The support hub operates 5 days per week, and makes use of the Outcomes Star framework to ensure there is a clear path for all individuals engaging with us, and the impact of our support can be measured, both for the client and the individual engaging with them.

Corporate Council

The development of our Corporate Council has been incredibly successful. We have 6 pharmaceutical companies engaged and signed up and have held a successful first meeting. We are delighted and grateful to have the support of industry and thank our Corporate Council members for their engagement and support.

Understanding Rare – Mental Health Training

We held 3 sessions of our new mental health awareness module. Over 60 people participated and provided very positive and constructive feedback. This module aimed at those who work with the general public in areas such as housing, benefits and social support, and aims to highlight some of the unique mental health difficulties a person with a rare condition might face at different stages of their journey through diagnosis and treatment.

Northern Ireland Rare Disease Implementation Group

NIRDP continues to be a key stakeholder with the NIRDIG working group alongside colleagues in Dept of Health, QUB, UU, HSC and others. We led workstream 5 this year to complete and submit a business case for a Rare Disease Champion role for NI. Currently, this has not been approved or funded and NIRDP will continue to work with Department of Health to ensure that people with a rare disease are represented and heard at government level.

All Party Group for Rare Disease

We have been delighted to have held the secretariat for the All Party Group (APG) for Rare Disease at Stormont. There have been a number of meetings over the period with elected MLA's and input from patients, carers and stakeholders to raise awareness of rare disease and ask questions of our elected representatives. We want to thank the APG members for their time and membership, in particular, the Chair, Mark H Durkan, and look forward to continuing this into next year.

Alongside the above, our team has been working on a refreshed website design, attending health conferences, events, and fairs to continue to raise awareness of rare disease and to ensure that those who need our support know that we exist and can help and support.

The trustees would like to thank the NIRDP team for their continued support and efforts in ensuring our key aim, which is to ensure that no one in Northern Ireland is disadvantaged due to the rarity of their health condition.

We also would like to thank our funders;

The National Lottery Community Fund

ARN Foundation

The Community Foundation NI

The Department of Health

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

Financial review

The charitable company generated a surplus for the year of £12,920 (2023: deficit £23,433), which included a deficit of unrestricted funds of £2,515 (2023: surplus £796) offset by a surplus of restricted funds of £15,435 (2023: deficit £24,229).

Reserves policy

The charitable company's ongoing reserves policy is to maintain a minimum level of reserves which matches the needs of the organisation both at the current time and in the foreseeable future. The trustees will strive to maintain reserves in the future, sufficient to meet statutory obligations, committed expenditure, core salaries and running costs equivalent to between three and six month's expenditure. The trustees consider that reserves at this level will ensure that, in the event of a significant drop in funding, they will be able to continue the charity's current activities while consideration is given to ways in which additional funds may be raised. This level of reserves has been maintained throughout the year.

Major risks

The trustees have a risk management strategy in place whereby major risks, to which the charity is exposed have been assessed, and Trustees are satisfied that systems are in place to mitigate exposure to the major risks. The risk management strategy comprises:

- an annual review of the risks the charity may face,
- the establishment of systems and procedures to mitigate those risks identified,
- financial risk is managed by the establishment of a reserves policy and its regular review by Trustees,
- attention is also focussed where necessary on the Protection of Children and Vulnerable Adults and Health & Safety in the workplace.

Structure, governance and management

The charity is a company limited by guarantee governed by its Memorandum and Articles of Association dated 22nd March 2021. The Northern Ireland Rare Disease Partnership (NIRDP) is a registered charity with the Charity Commission for Northern Ireland, Number 105261. In the event of the company being wound up members are required to contribute an amount not exceeding £1.

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

S M Duddy-Duguez	(Resigned 30 June 2023)
C Donnelly	(Resigned 1 June 2024)
A Phillips	(Resigned 24 May 2023)
S Callaghan	
A O'Loan	
J Wright	(Resigned 1 May 2024)
J McEvoy	
C McKenna	
Dr N Chaudhuri	

Recruitment and appointment of trustees

The recruitment procedures for new Trustees are laid out in the NIRDP's Memorandum and Articles of Association. New trustees are recruited based on the relevance of their professional skills and their potential to be able to make a helpful contribution to the governance of NIRDP. As part of the recruitment process they are made aware of a Trustee's legal obligations under charity and company law, the content of the Memorandum and Articles of Association, the charity's decision-making processes, the Strategic Plan and recent financial performance of the charity.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

Organisational structure

NIRDP has a Board of 5 Trustees, who meet at least quarterly and are responsible for the strategic direction and running of the charity. In delivering the objectives of the charity, a Chief Executive Officer is appointed by the Trustees to manage the day-to-day operations of the charity and they are supported by other members of staff.

The trustees' report was approved by the Board of Trustees.



[Sarah Callaghan \(Dec 23, 2024 10:13 GMT\)](#)

S Callaghan

Director

23 December 2024



[Anne-Marie O'Loan \(Dec 23, 2024 22:28 GMT\)](#)

A O'Loan

Director

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF NORTHERN IRELAND RARE DISEASE PARTNERSHIP

I report to the trustees on my examination of the financial statements of Northern Ireland Rare Disease Partnership (the charity) for the year ended 31 March 2024.

Responsibilities and basis of report

As the trustees of the charity (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 (the 2006 Act).

Having satisfied myself that the charity is not subject to audit under company law, and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 65 of the Charities Act
- follow the procedures laid down in the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act
- state whether particular matters have come to my attention.

Independent examiner's statement

I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in accordance with the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act. The examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1 accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
- 4 the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the financial statements to be reached.

Paula Armstrong

[Paula Armstrong \(Dec 23, 2024 09:52 GMT\)](#)

Paula Armstrong

For and on behalf of MTS Prior McMahon

Chartered Accountants
104-108 Frances Street
Newtownards
Down
BT23 7DY

Dated: 23 December 2024

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2024

	Notes	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
Income from:							
Donations and legacies	2	9,700	52,000	61,700	10,985	38,239	49,224
Total income		9,700	52,000	61,700	10,985	38,239	49,224
Expenditure on:							
Charitable activities	3	12,215	36,565	48,780	10,189	62,468	72,657
Total expenditure		12,215	36,565	48,780	10,189	62,468	72,657
Net income/(expenditure) and movement in funds		(2,515)	15,435	12,920	796	(24,229)	(23,433)
Reconciliation of funds:							
Fund balances at 1 April 2023		19,272	12,728	32,000	18,476	36,957	55,433
Fund balances at 31 March 2024		16,757	28,163	44,920	19,272	12,728	32,000

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

BALANCE SHEET

AS AT 31 MARCH 2024

	Notes	2024		2023	
		£	£	£	£
Fixed assets					
Tangible assets	7		1,546		1,811
Current assets					
Debtors	8	10,000		1,307	
Cash at bank and in hand		34,966		32,991	
		<u>44,966</u>		<u>34,298</u>	
Creditors: amounts falling due within one year	9	<u>(1,592)</u>		<u>(4,109)</u>	
Net current assets			43,374		30,189
Total assets less current liabilities			<u>44,920</u>		<u>32,000</u>
Net assets excluding pension liability			<u>44,920</u>		<u>32,000</u>
			<u><u> </u></u>		<u><u> </u></u>
The funds of the charity					
Restricted income funds	11	28,163		12,728	
Unrestricted funds		16,757		19,272	
		<u>44,920</u>		<u>32,000</u>	
		<u><u> </u></u>		<u><u> </u></u>	


The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 March 2024.

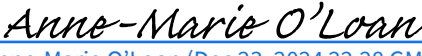
The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the trustees on 23 December 2024


Saran Callaghan (Dec 23, 2024 10:13 GMT)
S Callaghan
Director


Anne-Marie O'Loan (Dec 23, 2024 22:28 GMT)
A O'Loan
Director

Company registration number NI611153 (Northern Ireland)

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2024

1 Accounting policies

Charity information

Northern Ireland Rare Disease Partnership is a private company limited by guarantee incorporated in Northern Ireland. The registered office is Guardian Chartered Accountants, 2 William Street, Newtownards, BT23 4AH.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's articles of association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2016). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, [modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value]. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors or grantors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

1 Accounting policies

(Continued)

1.5 Resources expended

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates;

- Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of and indirect nature necessary to support them.

- Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees and costs linked to the strategic management of the charity.

All costs are allocated between the expenditure categories of the SOFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, others are apportioned on an appropriate basis.

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	25% reducing balance
-----------------------	----------------------

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

1.7 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.8 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.9 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

1 Accounting policies

(Continued)

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.10 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

1.11 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

2 Donations and legacies

	Unrestricted funds	Restricted funds	Total	Total
	2024	2024	2024	2023
	£	£	£	£
Donations and gifts	2,186	-	2,186	10,985
Grants	4,014	52,000	56,014	38,239
Membership fees	3,500	-	3,500	-
	<u>9,700</u>	<u>52,000</u>	<u>61,700</u>	<u>49,224</u>
For the year ended 31 March 2023	<u>10,985</u>	<u>38,239</u>		<u>49,224</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

2 Donations and legacies

(Continued)

Donations and gifts

Donations	-	-	-	10,943
Other	2,186	-	2,186	42
	<u>2,186</u>	<u>-</u>	<u>2,186</u>	<u>10,985</u>

3 Charitable activities

	2024 £	2023 £
Staff costs	35,809	59,193
Staff and board training	-	1,222
Subscriptions	115	65
Insurance	96	96
Printing, postage and stationery	-	803
Advertising and promotional costs	-	853
Telephone	88	172
Computer and internet costs	2,188	2,514
Motor and travel expenses	659	2,127
Consultancy	7,501	3,125
Event expenses	41	886
General expenses	823	389
	<u>47,320</u>	<u>71,445</u>
Share of governance costs (see note 4)	1,460	1,212
	<u>48,780</u>	<u>72,657</u>
Analysis by fund		
Unrestricted funds	12,215	10,189
Restricted funds	36,565	62,468
	<u>48,780</u>	<u>72,657</u>

4 Governance costs

	Restricted £	Unrestricted £	2024 £	2023 £
Governance costs heading 1	-	887	887	540
Bank charges	-	58	58	68
Depreciation	-	515	515	604
	<u>-</u>	<u>1,460</u>	<u>1,460</u>	<u>1,212</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

5 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

6 Employees

The average monthly number of employees during the year was:

	2024	2023
	Number	Number
	3	4
	<u> </u>	<u> </u>
Employment costs	2024	2023
	£	£
Wages and salaries	35,211	58,542
Other pension costs	598	651
	<u> </u>	<u> </u>
	<u>35,809</u>	<u>59,193</u>

There were no employees whose annual remuneration was more than £60,000.

Remuneration of key management personnel

The remuneration of key management personnel was as follows:

7 Tangible fixed assets

	Fixtures and fittings
	£
Cost	
At 1 April 2023	4,607
Additions	250
	<u> </u>
At 31 March 2024	4,857
	<u> </u>
Depreciation and impairment	
At 1 April 2023	2,796
Depreciation charged in the year	515
	<u> </u>
At 31 March 2024	3,311
	<u> </u>
Carrying amount	
At 31 March 2024	1,546
	<u> </u>
At 31 March 2023	1,811
	<u> </u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

8 Debtors	2024	2023
	£	£
Amounts falling due within one year:		
Trade debtors	10,000	-
Other debtors	-	1,307
	<u>10,000</u>	<u>1,307</u>
	<u><u>10,000</u></u>	<u><u>1,307</u></u>
9 Creditors: amounts falling due within one year	2024	2023
	£	£
Other taxation and social security	387	729
Other creditors	-	1,594
Accruals and deferred income	1,205	1,786
	<u>1,592</u>	<u>4,109</u>
	<u><u>1,592</u></u>	<u><u>4,109</u></u>
10 Retirement benefit schemes	2024	2023
	£	£
Defined contribution schemes		
Charge to profit or loss in respect of defined contribution schemes	598	651
	<u>598</u>	<u>651</u>
	<u><u>598</u></u>	<u><u>651</u></u>

The charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the charity in an independently administered fund.

11 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 1 April 2023 £	Incoming resources £	Resources expended £	At 31 March 2024 £
	12,728	52,000	(36,565)	28,163
	<u>12,728</u>	<u>52,000</u>	<u>(36,565)</u>	<u>28,163</u>
	<u><u>12,728</u></u>	<u><u>52,000</u></u>	<u><u>(36,565)</u></u>	<u><u>28,163</u></u>
Previous year:	At 1 April 2022 £	Incoming resources £	Resources expended £	At 31 March 2023 £
	36,957	38,239	(62,468)	12,728
	<u>36,957</u>	<u>38,239</u>	<u>(62,468)</u>	<u>12,728</u>
	<u><u>36,957</u></u>	<u><u>38,239</u></u>	<u><u>(62,468)</u></u>	<u><u>12,728</u></u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

12 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 April 2023	Incoming resources	Resources expended	At 31 March 2024
	£	£	£	£
General funds	19,272	9,700	(12,215)	16,757
	<u> </u>	<u> </u>	<u> </u>	<u> </u>
Previous year:	At 1 April 2022	Incoming resources	Resources expended	At 31 March 2023
	£	£	£	£
General funds	18,476	10,985	(10,189)	19,272
	<u> </u>	<u> </u>	<u> </u>	<u> </u>

13 Related party transactions

There were no disclosable related party transactions during the year (2023 - none).












NIRDP Accounts for signing


Final Audit Report

2024-12-23


Created:	2024-12-23
By:	June Stevenson (June@mtsaccountants.com)
Status:	Signed
Transaction ID:	CBJCHBCAABAAPysW8rkkEC3WmF3RsNGFALQoC0EKmAOr

"NIRDP Accounts for signing" History

-  Document created by June Stevenson (June@mtsaccountants.com)
2024-12-23 - 09:27:53 GMT
-  Document emailed to paula@mtsaccountants.com for signature
2024-12-23 - 09:30:47 GMT
-  Email viewed by paula@mtsaccountants.com
2024-12-23 - 09:31:50 GMT
-  Signer paula@mtsaccountants.com entered name at signing as Paula Armstrong
2024-12-23 - 09:32:31 GMT
-  Document e-signed by Paula Armstrong (paula@mtsaccountants.com)
Signature Date: 2024-12-23 - 09:32:33 GMT - Time Source: server
-  Document emailed to chair@nirdp.org.uk for signature
2024-12-23 - 09:32:34 GMT
-  Email viewed by chair@nirdp.org.uk
2024-12-23 - 10:12:10 GMT
-  Signer chair@nirdp.org.uk entered name at signing as Sarah Callaghan
2024-12-23 - 10:13:12 GMT
-  Document e-signed by Sarah Callaghan (chair@nirdp.org.uk)
Signature Date: 2024-12-23 - 10:13:14 GMT - Time Source: server
-  Document emailed to amoloan@nirdp.org.uk for signature
2024-12-23 - 10:13:16 GMT
-  Email viewed by amoloan@nirdp.org.uk
2024-12-23 - 22:25:25 GMT

 Signer amoloan@nirdp.org.uk entered name at signing as Anne-Marie O'Loan
2024-12-23 - 22:28:14 GMT

 Document e-signed by Anne-Marie O'Loan (amoloan@nirdp.org.uk)
Signature Date: 2024-12-23 - 22:28:16 GMT - Time Source: server

 Agreement completed.
2024-12-23 - 22:28:16 GMT

Northern Ireland Rare Disease Partnership

Northern Ireland - Charity number 105261

Annual report

Our Ref: PA/JS
Date: 23 December 2024
Code: PM1015
ID: 189527

The Trustees
Northern Ireland Rare Disease Partnership
Guardian Chartered Accountants
2 William Street
Newtownards
BT23 4AH

Dear Sarah & Anne Marie

Please find attached PDF of the following document that requires your electronic signatures.

1. Accounts for the year ended 31 March 2024.

Yours sincerely


Paula Armstrong
Paula Armstrong (Dec 23, 2024 09:52 GMT)

Mrs Paula Armstrong
On behalf of MTS Chartered Accountants

Enc

MTS Chartered Accountants
1 Lanyon Quay
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T +44 (0)28 9032 3040
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Registered to carry out audit work by the
Institute of Chartered Accountants in Ireland



Registered with The Chartered Institute of
Taxation as a firm of Chartered Tax Advisors

www.mtsaccountants.com – A full list of Directors of
McCreery Turkington Stockman Ltd is available at our website.

N.I. Registration No. NI626535.
MTS Chartered Accountants & MTS Prior McMahon
are trading names of McCreery Turkington Stockman Ltd.

Charity registration number 105261

Company registration number NI611153 (Northern Ireland)

**NORTHERN IRELAND RARE DISEASE PARTNERSHIP
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	S Callaghan A O'Loan J McEvoy C McKenna Dr N Chaudhuri
Charity number	105261
Company number	NI611153
Registered office	Guardian Chartered Accountants 2 William Street Newtownards BT23 4AH
Independent examiner	MTS Prior McMahon 104-108 Frances Street Newtownards Down BT23 7DY

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

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Statement of financial activities	6
Balance sheet	7
Notes to the financial statements	8 - 14

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

FOR THE YEAR ENDED 31 MARCH 2024

The trustees present their annual report and financial statements for the year ended 31 March 2024.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's Memorandum and Articles of association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (effective 1 January 2019).

Objectives and activities

There are 3 key objectives of the charity, as defined in the governing document, and they are:

1. To support and campaign on behalf of those persons in Northern Ireland ("the area of benefit") affected by or believed to be affected by a rare disease and their families, dependents, and carers.
2. To advance the education of the public and of relevant professionals and policy makers in all matters concerning rare diseases.
3. To advance any other exclusively charitable purpose as the trustees may, from time to time, decide in accordance with the law of charity.

Public benefit

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake. The Trustees believe that the charitable organisation provides a public benefit in a number of ways through the undertaking of a range of projects and by providing support to all persons affected by a rare disease including individuals, families, dependents and carers. The direct benefit that will flow from this benefit will be to improve the diagnosis, treatment, and support of individuals affected by rare diseases.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

Achievements and performance

Significant activities and achievements against objectives

The trustees are delighted to share the progress and achievements of the charity below.

Virtual Support Hub

Our support hub continues to be a vital source of information and support for the rare disease community in NI. Over 100 people have contacted the team for advice, guidance and practical help in areas including, benefits, health service navigation, access to condition specific information and wellbeing/mental health support and signposting. The support hub operates 5 days per week, and makes use of the Outcomes Star framework to ensure there is a clear path for all individuals engaging with us, and the impact of our support can be measured, both for the client and the individual engaging with them.

Corporate Council

The development of our Corporate Council has been incredibly successful. We have 6 pharmaceutical companies engaged and signed up and have held a successful first meeting. We are delighted and grateful to have the support of industry and thank our Corporate Council members for their engagement and support.

Understanding Rare – Mental Health Training

We held 3 sessions of our new mental health awareness module. Over 60 people participated and provided very positive and constructive feedback. This module aimed at those who work with the general public in areas such as housing, benefits and social support, and aims to highlight some of the unique mental health difficulties a person with a rare condition might face at different stages of their journey through diagnosis and treatment.

Northern Ireland Rare Disease Implementation Group

NIRDP continues to be a key stakeholder with the NIRDIG working group alongside colleagues in Dept of Health, QUB, UU, HSC and others. We led workstream 5 this year to complete and submit a business case for a Rare Disease Champion role for NI. Currently, this has not been approved or funded and NIRDP will continue to work with Department of Health to ensure that people with a rare disease are represented and heard at government level.

All Party Group for Rare Disease

We have been delighted to have held the secretariat for the All Party Group (APG) for Rare Disease at Stormont. There have been a number of meetings over the period with elected MLA's and input from patients, carers and stakeholders to raise awareness of rare disease and ask questions of our elected representatives. We want to thank the APG members for their time and membership, in particular, the Chair, Mark H Durkan, and look forward to continuing this into next year.

Alongside the above, our team has been working on a refreshed website design, attending health conferences, events, and fairs to continue to raise awareness of rare disease and to ensure that those who need our support know that we exist and can help and support.

The trustees would like to thank the NIRDP team for their continued support and efforts in ensuring our key aim, which is to ensure that no one in Northern Ireland is disadvantaged due to the rarity of their health condition.

We also would like to thank our funders;

The National Lottery Community Fund

ARN Foundation

The Community Foundation NI

The Department of Health

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

Financial review

The charitable company generated a surplus for the year of £12,920 (2023: deficit £23,433), which included a deficit of unrestricted funds of £2,515 (2023: surplus £796) offset by a surplus of restricted funds of £15,435 (2023: deficit £24,229).

Reserves policy

The charitable company's ongoing reserves policy is to maintain a minimum level of reserves which matches the needs of the organisation both at the current time and in the foreseeable future. The trustees will strive to maintain reserves in the future, sufficient to meet statutory obligations, committed expenditure, core salaries and running costs equivalent to between three and six month's expenditure. The trustees consider that reserves at this level will ensure that, in the event of a significant drop in funding, they will be able to continue the charity's current activities while consideration is given to ways in which additional funds may be raised. This level of reserves has been maintained throughout the year.

Major risks

The trustees have a risk management strategy in place whereby major risks, to which the charity is exposed have been assessed, and Trustees are satisfied that systems are in place to mitigate exposure to the major risks. The risk management strategy comprises:

- an annual review of the risks the charity may face,
- the establishment of systems and procedures to mitigate those risks identified,
- financial risk is managed by the establishment of a reserves policy and its regular review by Trustees,
- attention is also focussed where necessary on the Protection of Children and Vulnerable Adults and Health & Safety in the workplace.

Structure, governance and management

The charity is a company limited by guarantee governed by its Memorandum and Articles of Association dated 22nd March 2021. The Northern Ireland Rare Disease Partnership (NIRDP) is a registered charity with the Charity Commission for Northern Ireland, Number 105261. In the event of the company being wound up members are required to contribute an amount not exceeding £1.

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

S M Duddy-Duguez	(Resigned 30 June 2023)
C Donnelly	(Resigned 1 June 2024)
A Phillips	(Resigned 24 May 2023)
S Callaghan	
A O'Loan	
J Wright	(Resigned 1 May 2024)
J McEvoy	
C McKenna	
Dr N Chaudhuri	

Recruitment and appointment of trustees

The recruitment procedures for new Trustees are laid out in the NIRDP's Memorandum and Articles of Association. New trustees are recruited based on the relevance of their professional skills and their potential to be able to make a helpful contribution to the governance of NIRDP. As part of the recruitment process they are made aware of a Trustee's legal obligations under charity and company law, the content of the Memorandum and Articles of Association, the charity's decision-making processes, the Strategic Plan and recent financial performance of the charity.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

Organisational structure

NIRDP has a Board of 5 Trustees, who meet at least quarterly and are responsible for the strategic direction and running of the charity. In delivering the objectives of the charity, a Chief Executive Officer is appointed by the Trustees to manage the day-to-day operations of the charity and they are supported by other members of staff.

The trustees' report was approved by the Board of Trustees.



[Sarah Callaghan \(Dec 23, 2024 10:13 GMT\)](#)

S Callaghan

Director

23 December 2024



[Anne-Marie O'Loan \(Dec 23, 2024 22:28 GMT\)](#)

A O'Loan

Director

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF NORTHERN IRELAND RARE DISEASE PARTNERSHIP

I report to the trustees on my examination of the financial statements of Northern Ireland Rare Disease Partnership (the charity) for the year ended 31 March 2024.

Responsibilities and basis of report

As the trustees of the charity (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 (the 2006 Act).

Having satisfied myself that the charity is not subject to audit under company law, and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 65 of the Charities Act
- follow the procedures laid down in the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act
- state whether particular matters have come to my attention.

Independent examiner's statement

I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in accordance with the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act. The examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1 accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
- 4 the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the financial statements to be reached.

Paula Armstrong

[Paula Armstrong \(Dec 23, 2024 09:52 GMT\)](#)

Paula Armstrong

For and on behalf of MTS Prior McMahon

Chartered Accountants
104-108 Frances Street
Newtownards
Down
BT23 7DY

Dated: 23 December 2024

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2024

	Notes	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
Income from:							
Donations and legacies	2	9,700	52,000	61,700	10,985	38,239	49,224
Total income		9,700	52,000	61,700	10,985	38,239	49,224
Expenditure on:							
Charitable activities	3	12,215	36,565	48,780	10,189	62,468	72,657
Total expenditure		12,215	36,565	48,780	10,189	62,468	72,657
Net income/(expenditure) and movement in funds		(2,515)	15,435	12,920	796	(24,229)	(23,433)
Reconciliation of funds:							
Fund balances at 1 April 2023		19,272	12,728	32,000	18,476	36,957	55,433
Fund balances at 31 March 2024		16,757	28,163	44,920	19,272	12,728	32,000

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

BALANCE SHEET

AS AT 31 MARCH 2024

	Notes	2024		2023	
		£	£	£	£
Fixed assets					
Tangible assets	7		1,546		1,811
Current assets					
Debtors	8	10,000		1,307	
Cash at bank and in hand		34,966		32,991	
		<u>44,966</u>		<u>34,298</u>	
Creditors: amounts falling due within one year	9	<u>(1,592)</u>		<u>(4,109)</u>	
Net current assets			43,374		30,189
Total assets less current liabilities			<u>44,920</u>		<u>32,000</u>
Net assets excluding pension liability			<u>44,920</u>		<u>32,000</u>
			<u><u> </u></u>		<u><u> </u></u>
The funds of the charity					
Restricted income funds	11	28,163		12,728	
Unrestricted funds		16,757		19,272	
		<u>44,920</u>		<u>32,000</u>	
		<u><u> </u></u>		<u><u> </u></u>	


The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 March 2024.

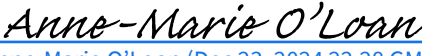
The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the trustees on 23 December 2024


Saran Callaghan (Dec 23, 2024 10:13 GMT)
S Callaghan
Director


Anne-Marie O'Loan (Dec 23, 2024 22:28 GMT)
A O'Loan
Director

Company registration number NI611153 (Northern Ireland)

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2024

1 Accounting policies

Charity information

Northern Ireland Rare Disease Partnership is a private company limited by guarantee incorporated in Northern Ireland. The registered office is Guardian Chartered Accountants, 2 William Street, Newtownards, BT23 4AH.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's articles of association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2016). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, [modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value]. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors or grantors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

1 Accounting policies

(Continued)

1.5 Resources expended

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates;

- Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of and indirect nature necessary to support them.

- Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees and costs linked to the strategic management of the charity.

All costs are allocated between the expenditure categories of the SOFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, others are apportioned on an appropriate basis.

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	25% reducing balance
-----------------------	----------------------

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

1.7 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.8 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.9 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

1 Accounting policies

(Continued)

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.10 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

1.11 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

2 Donations and legacies

	Unrestricted funds	Restricted funds	Total	Total
	2024	2024	2024	2023
	£	£	£	£
Donations and gifts	2,186	-	2,186	10,985
Grants	4,014	52,000	56,014	38,239
Membership fees	3,500	-	3,500	-
	<u>9,700</u>	<u>52,000</u>	<u>61,700</u>	<u>49,224</u>
For the year ended 31 March 2023	<u>10,985</u>	<u>38,239</u>		<u>49,224</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

2 Donations and legacies

(Continued)

Donations and gifts

Donations	-	-	-	10,943
Other	2,186	-	2,186	42
	<u>2,186</u>	<u>-</u>	<u>2,186</u>	<u>10,985</u>

3 Charitable activities

	2024	2023
	£	£
Staff costs	35,809	59,193
Staff and board training	-	1,222
Subscriptions	115	65
Insurance	96	96
Printing, postage and stationery	-	803
Advertising and promotional costs	-	853
Telephone	88	172
Computer and internet costs	2,188	2,514
Motor and travel expenses	659	2,127
Consultancy	7,501	3,125
Event expenses	41	886
General expenses	823	389
	<u>47,320</u>	<u>71,445</u>
Share of governance costs (see note 4)	1,460	1,212
	<u>48,780</u>	<u>72,657</u>
Analysis by fund		
Unrestricted funds	12,215	10,189
Restricted funds	36,565	62,468
	<u>48,780</u>	<u>72,657</u>

4 Governance costs

	Restricted	Unrestricted	2024	2023
	£	£	£	£
Governance costs heading 1	-	887	887	540
Bank charges	-	58	58	68
Depreciation	-	515	515	604
	<u>-</u>	<u>1,460</u>	<u>1,460</u>	<u>1,212</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

5 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

6 Employees

The average monthly number of employees during the year was:

	2024	2023
	Number	Number
	3	4
	<u> </u>	<u> </u>
Employment costs	2024	2023
	£	£
Wages and salaries	35,211	58,542
Other pension costs	598	651
	<u> </u>	<u> </u>
	<u>35,809</u>	<u>59,193</u>

There were no employees whose annual remuneration was more than £60,000.

Remuneration of key management personnel

The remuneration of key management personnel was as follows:

7 Tangible fixed assets

	Fixtures and fittings
	£
Cost	
At 1 April 2023	4,607
Additions	250
	<u> </u>
At 31 March 2024	4,857
	<u> </u>
Depreciation and impairment	
At 1 April 2023	2,796
Depreciation charged in the year	515
	<u> </u>
At 31 March 2024	3,311
	<u> </u>
Carrying amount	
At 31 March 2024	1,546
	<u> </u>
At 31 March 2023	1,811
	<u> </u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

8 Debtors		2024	2023
		£	£
Amounts falling due within one year:			
Trade debtors		10,000	-
Other debtors		-	1,307
		<u>10,000</u>	<u>1,307</u>
		<u><u>10,000</u></u>	<u><u>1,307</u></u>
9 Creditors: amounts falling due within one year		2024	2023
		£	£
Other taxation and social security		387	729
Other creditors		-	1,594
Accruals and deferred income		1,205	1,786
		<u>1,592</u>	<u>4,109</u>
		<u><u>1,592</u></u>	<u><u>4,109</u></u>
10 Retirement benefit schemes		2024	2023
		£	£
Defined contribution schemes			
Charge to profit or loss in respect of defined contribution schemes		598	651
		<u>598</u>	<u>651</u>
		<u><u>598</u></u>	<u><u>651</u></u>

The charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the charity in an independently administered fund.

11 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 1 April	Incoming	Resources	At 31 March
	2023	resources	expended	2024
	£	£	£	£
	12,728	52,000	(36,565)	28,163
	<u>12,728</u>	<u>52,000</u>	<u>(36,565)</u>	<u>28,163</u>
Previous year:	At 1 April	Incoming	Resources	At 31 March
	2022	resources	expended	2023
	£	£	£	£
	36,957	38,239	(62,468)	12,728
	<u>36,957</u>	<u>38,239</u>	<u>(62,468)</u>	<u>12,728</u>
	<u><u>36,957</u></u>	<u><u>38,239</u></u>	<u><u>(62,468)</u></u>	<u><u>12,728</u></u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

12 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 April 2023 £	Incoming resources £	Resources expended £	At 31 March 2024 £
General funds	19,272	9,700	(12,215)	16,757
	<u> </u>	<u> </u>	<u> </u>	<u> </u>
Previous year:	At 1 April 2022 £	Incoming resources £	Resources expended £	At 31 March 2023 £
General funds	18,476	10,985	(10,189)	19,272
	<u> </u>	<u> </u>	<u> </u>	<u> </u>

13 Related party transactions

There were no disclosable related party transactions during the year (2023 - none).












NIRDP Accounts for signing


Final Audit Report


2024-12-23


Created:	2024-12-23
By:	June Stevenson (June@mtsaccountants.com)
Status:	Signed
Transaction ID:	CBJCHBCAABAAPysW8rkkEC3WmF3RsNGFALQoC0EKmAOr

"NIRDP Accounts for signing" History

-  Document created by June Stevenson (June@mtsaccountants.com)
2024-12-23 - 09:27:53 GMT
-  Document emailed to paula@mtsaccountants.com for signature
2024-12-23 - 09:30:47 GMT
-  Email viewed by paula@mtsaccountants.com
2024-12-23 - 09:31:50 GMT
-  Signer paula@mtsaccountants.com entered name at signing as Paula Armstrong
2024-12-23 - 09:32:31 GMT
-  Document e-signed by Paula Armstrong (paula@mtsaccountants.com)
Signature Date: 2024-12-23 - 09:32:33 GMT - Time Source: server
-  Document emailed to chair@nirdp.org.uk for signature
2024-12-23 - 09:32:34 GMT
-  Email viewed by chair@nirdp.org.uk
2024-12-23 - 10:12:10 GMT
-  Signer chair@nirdp.org.uk entered name at signing as Sarah Callaghan
2024-12-23 - 10:13:12 GMT
-  Document e-signed by Sarah Callaghan (chair@nirdp.org.uk)
Signature Date: 2024-12-23 - 10:13:14 GMT - Time Source: server
-  Document emailed to amoloan@nirdp.org.uk for signature
2024-12-23 - 10:13:16 GMT
-  Email viewed by amoloan@nirdp.org.uk
2024-12-23 - 22:25:25 GMT

 Signer amoloan@nirdp.org.uk entered name at signing as Anne-Marie O'Loan
2024-12-23 - 22:28:14 GMT

 Document e-signed by Anne-Marie O'Loan (amoloan@nirdp.org.uk)
Signature Date: 2024-12-23 - 22:28:16 GMT - Time Source: server

 Agreement completed.
2024-12-23 - 22:28:16 GMT

Northern Ireland Rare Disease Partnership

Northern Ireland - Charity number 105261

Annual return

Our Ref: PA/JS
Date: 23 December 2024
Code: PM1015
ID: 189527

The Trustees
Northern Ireland Rare Disease Partnership
Guardian Chartered Accountants
2 William Street
Newtownards
BT23 4AH

Dear Sarah & Anne Marie

Please find attached PDF of the following document that requires your electronic signatures.

1. Accounts for the year ended 31 March 2024.

Yours sincerely


[Paula Armstrong \(Dec 23, 2024 09:52 GMT\)](#)

Mrs Paula Armstrong
On behalf of MTS Chartered Accountants

Enc

MTS Chartered Accountants
1 Lanyon Quay
Belfast
BT1 3LG
T +44 (0)28 9032 3040
E info@mtsaccountants.com

MTS Chartered Accountants Holywood
T +44(0)28 9042 2401
E holywood@mtsaccountants.com

MTS Prior McMahon
T +44(0)28 9181 3123
E info@mtsaccountants.com



Registered to carry out audit work by the
Institute of Chartered Accountants in Ireland



Registered with The Chartered Institute of
Taxation as a firm of Chartered Tax Advisors

www.mtsaccountants.com – A full list of Directors of
McCreery Turkington Stockman Ltd is available at our website.

N.I. Registration No. NI626535.
MTS Chartered Accountants & MTS Prior McMahon
are trading names of McCreery Turkington Stockman Ltd.

Charity registration number 105261

Company registration number NI611153 (Northern Ireland)

**NORTHERN IRELAND RARE DISEASE PARTNERSHIP
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2024**

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	S Callaghan A O'Loan J McEvoy C McKenna Dr N Chaudhuri
Charity number	105261
Company number	NI611153
Registered office	Guardian Chartered Accountants 2 William Street Newtownards BT23 4AH
Independent examiner	MTS Prior McMahon 104-108 Frances Street Newtownards Down BT23 7DY

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

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Statement of financial activities	6
Balance sheet	7
Notes to the financial statements	8 - 14

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT)

FOR THE YEAR ENDED 31 MARCH 2024

The trustees present their annual report and financial statements for the year ended 31 March 2024.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's Memorandum and Articles of association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (effective 1 January 2019).

Objectives and activities

There are 3 key objectives of the charity, as defined in the governing document, and they are:

1. To support and campaign on behalf of those persons in Northern Ireland ("the area of benefit") affected by or believed to be affected by a rare disease and their families, dependents, and carers.
2. To advance the education of the public and of relevant professionals and policy makers in all matters concerning rare diseases.
3. To advance any other exclusively charitable purpose as the trustees may, from time to time, decide in accordance with the law of charity.

Public benefit

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake. The Trustees believe that the charitable organisation provides a public benefit in a number of ways through the undertaking of a range of projects and by providing support to all persons affected by a rare disease including individuals, families, dependents and carers. The direct benefit that will flow from this benefit will be to improve the diagnosis, treatment, and support of individuals affected by rare diseases.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

Achievements and performance

Significant activities and achievements against objectives

The trustees are delighted to share the progress and achievements of the charity below.

Virtual Support Hub

Our support hub continues to be a vital source of information and support for the rare disease community in NI. Over 100 people have contacted the team for advice, guidance and practical help in areas including, benefits, health service navigation, access to condition specific information and wellbeing/mental health support and signposting. The support hub operates 5 days per week, and makes use of the Outcomes Star framework to ensure there is a clear path for all individuals engaging with us, and the impact of our support can be measured, both for the client and the individual engaging with them.

Corporate Council

The development of our Corporate Council has been incredibly successful. We have 6 pharmaceutical companies engaged and signed up and have held a successful first meeting. We are delighted and grateful to have the support of industry and thank our Corporate Council members for their engagement and support.

Understanding Rare – Mental Health Training

We held 3 sessions of our new mental health awareness module. Over 60 people participated and provided very positive and constructive feedback. This module aimed at those who work with the general public in areas such as housing, benefits and social support, and aims to highlight some of the unique mental health difficulties a person with a rare condition might face at different stages of their journey through diagnosis and treatment.

Northern Ireland Rare Disease Implementation Group

NIRDP continues to be a key stakeholder with the NIRDIG working group alongside colleagues in Dept of Health, QUB, UU, HSC and others. We led workstream 5 this year to complete and submit a business case for a Rare Disease Champion role for NI. Currently, this has not been approved or funded and NIRDP will continue to work with Department of Health to ensure that people with a rare disease are represented and heard at government level.

All Party Group for Rare Disease

We have been delighted to have held the secretariat for the All Party Group (APG) for Rare Disease at Stormont. There have been a number of meetings over the period with elected MLA's and input from patients, carers and stakeholders to raise awareness of rare disease and ask questions of our elected representatives. We want to thank the APG members for their time and membership, in particular, the Chair, Mark H Durkan, and look forward to continuing this into next year.

Alongside the above, our team has been working on a refreshed website design, attending health conferences, events, and fairs to continue to raise awareness of rare disease and to ensure that those who need our support know that we exist and can help and support.

The trustees would like to thank the NIRDP team for their continued support and efforts in ensuring our key aim, which is to ensure that no one in Northern Ireland is disadvantaged due to the rarity of their health condition.

We also would like to thank our funders;

The National Lottery Community Fund

ARN Foundation

The Community Foundation NI

The Department of Health

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

Financial review

The charitable company generated a surplus for the year of £12,920 (2023: deficit £23,433), which included a deficit of unrestricted funds of £2,515 (2023: surplus £796) offset by a surplus of restricted funds of £15,435 (2023: deficit £24,229).

Reserves policy

The charitable company's ongoing reserves policy is to maintain a minimum level of reserves which matches the needs of the organisation both at the current time and in the foreseeable future. The trustees will strive to maintain reserves in the future, sufficient to meet statutory obligations, committed expenditure, core salaries and running costs equivalent to between three and six month's expenditure. The trustees consider that reserves at this level will ensure that, in the event of a significant drop in funding, they will be able to continue the charity's current activities while consideration is given to ways in which additional funds may be raised. This level of reserves has been maintained throughout the year.

Major risks

The trustees have a risk management strategy in place whereby major risks, to which the charity is exposed have been assessed, and Trustees are satisfied that systems are in place to mitigate exposure to the major risks. The risk management strategy comprises:

- an annual review of the risks the charity may face,
- the establishment of systems and procedures to mitigate those risks identified,
- financial risk is managed by the establishment of a reserves policy and its regular review by Trustees,
- attention is also focussed where necessary on the Protection of Children and Vulnerable Adults and Health & Safety in the workplace.

Structure, governance and management

The charity is a company limited by guarantee governed by its Memorandum and Articles of Association dated 22nd March 2021. The Northern Ireland Rare Disease Partnership (NIRDP) is a registered charity with the Charity Commission for Northern Ireland, Number 105261. In the event of the company being wound up members are required to contribute an amount not exceeding £1.

The trustees, who are also the directors for the purpose of company law, and who served during the year and up to the date of signature of the financial statements were:

S M Duddy-Duguez	(Resigned 30 June 2023)
C Donnelly	(Resigned 1 June 2024)
A Phillips	(Resigned 24 May 2023)
S Callaghan	
A O'Loan	
J Wright	(Resigned 1 May 2024)
J McEvoy	
C McKenna	
Dr N Chaudhuri	

Recruitment and appointment of trustees

The recruitment procedures for new Trustees are laid out in the NIRDP's Memorandum and Articles of Association. New trustees are recruited based on the relevance of their professional skills and their potential to be able to make a helpful contribution to the governance of NIRDP. As part of the recruitment process they are made aware of a Trustee's legal obligations under charity and company law, the content of the Memorandum and Articles of Association, the charity's decision-making processes, the Strategic Plan and recent financial performance of the charity.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

TRUSTEES' REPORT (INCLUDING DIRECTORS' REPORT) (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2024

Organisational structure

NIRDP has a Board of 5 Trustees, who meet at least quarterly and are responsible for the strategic direction and running of the charity. In delivering the objectives of the charity, a Chief Executive Officer is appointed by the Trustees to manage the day-to-day operations of the charity and they are supported by other members of staff.

The trustees' report was approved by the Board of Trustees.



[Sarah Callaghan \(Dec 23, 2024 10:13 GMT\)](#)

S Callaghan

Director

23 December 2024



[Anne-Marie O'Loan \(Dec 23, 2024 22:28 GMT\)](#)

A O'Loan

Director

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF NORTHERN IRELAND RARE DISEASE PARTNERSHIP

I report to the trustees on my examination of the financial statements of Northern Ireland Rare Disease Partnership (the charity) for the year ended 31 March 2024.

Responsibilities and basis of report

As the trustees of the charity (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 (the 2006 Act).

Having satisfied myself that the charity is not subject to audit under company law, and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 65 of the Charities Act
- follow the procedures laid down in the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act
- state whether particular matters have come to my attention.

Independent examiner's statement

I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in accordance with the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act. The examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1 accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
- 4 the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the financial statements to be reached.

Paula Armstrong

[Paula Armstrong \(Dec 23, 2024 09:52 GMT\)](#)

Paula Armstrong

For and on behalf of MTS Prior McMahon

Chartered Accountants
104-108 Frances Street
Newtownards
Down
BT23 7DY

Dated: 23 December 2024

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2024

	Notes	Unrestricted funds 2024 £	Restricted funds 2024 £	Total 2024 £	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £
Income from:							
Donations and legacies	2	9,700	52,000	61,700	10,985	38,239	49,224
Total income		9,700	52,000	61,700	10,985	38,239	49,224
Expenditure on:							
Charitable activities	3	12,215	36,565	48,780	10,189	62,468	72,657
Total expenditure		12,215	36,565	48,780	10,189	62,468	72,657
Net income/(expenditure) and movement in funds		(2,515)	15,435	12,920	796	(24,229)	(23,433)
Reconciliation of funds:							
Fund balances at 1 April 2023		19,272	12,728	32,000	18,476	36,957	55,433
Fund balances at 31 March 2024		16,757	28,163	44,920	19,272	12,728	32,000

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derive from continuing activities.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

BALANCE SHEET

AS AT 31 MARCH 2024

	Notes	2024 £	£	2023 £	£
Fixed assets					
Tangible assets	7		1,546		1,811
Current assets					
Debtors	8	10,000		1,307	
Cash at bank and in hand		34,966		32,991	
		<u>44,966</u>		<u>34,298</u>	
Creditors: amounts falling due within one year	9	(1,592)		(4,109)	
Net current assets			43,374		30,189
Total assets less current liabilities			<u>44,920</u>		<u>32,000</u>
Net assets excluding pension liability			<u>44,920</u>		<u>32,000</u>
			<u><u> </u></u>		<u><u> </u></u>
The funds of the charity					
Restricted income funds	11	28,163		12,728	
Unrestricted funds		16,757		19,272	
		<u>44,920</u>		<u>32,000</u>	
		<u><u> </u></u>		<u><u> </u></u>	


The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 March 2024.

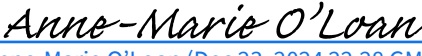
The directors acknowledge their responsibilities for complying with the requirements of the Companies Act 2006 with respect to accounting records and the preparation of financial statements.

The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the trustees on 23 December 2024


Saran Callaghan (Dec 23, 2024 10:13 GMT)
S Callaghan
Director


Anne-Marie O'Loan (Dec 23, 2024 22:28 GMT)
A O'Loan
Director

Company registration number NI611153 (Northern Ireland)

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2024

1 Accounting policies

Charity information

Northern Ireland Rare Disease Partnership is a private company limited by guarantee incorporated in Northern Ireland. The registered office is Guardian Chartered Accountants, 2 William Street, Newtownards, BT23 4AH.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's articles of association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2016). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, [modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value]. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors or grantors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

1 Accounting policies

(Continued)

1.5 Resources expended

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates;

- Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

- Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees and costs linked to the strategic management of the charity.

All costs are allocated between the expenditure categories of the SOFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, others are apportioned on an appropriate basis.

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	25% reducing balance
-----------------------	----------------------

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in the statement of financial activities.

1.7 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.8 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.9 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

1 Accounting policies

(Continued)

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.10 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

1.11 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

2 Donations and legacies

	Unrestricted funds	Restricted funds	Total	Total
	2024 £	2024 £	2024 £	2023 £
Donations and gifts	2,186	-	2,186	10,985
Grants	4,014	52,000	56,014	38,239
Membership fees	3,500	-	3,500	-
	<u>9,700</u>	<u>52,000</u>	<u>61,700</u>	<u>49,224</u>
For the year ended 31 March 2023	<u>10,985</u>	<u>38,239</u>		<u>49,224</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

2 Donations and legacies (Continued)

Donations and gifts

Donations	-	-	-	10,943
Other	2,186	-	2,186	42
	<u>2,186</u>	<u>-</u>	<u>2,186</u>	<u>10,985</u>

3 Charitable activities

	2024 £	2023 £
Staff costs	35,809	59,193
Staff and board training	-	1,222
Subscriptions	115	65
Insurance	96	96
Printing, postage and stationery	-	803
Advertising and promotional costs	-	853
Telephone	88	172
Computer and internet costs	2,188	2,514
Motor and travel expenses	659	2,127
Consultancy	7,501	3,125
Event expenses	41	886
General expenses	823	389
	<u>47,320</u>	<u>71,445</u>
Share of governance costs (see note 4)	1,460	1,212
	<u>48,780</u>	<u>72,657</u>
Analysis by fund		
Unrestricted funds	12,215	10,189
Restricted funds	36,565	62,468
	<u>48,780</u>	<u>72,657</u>

4 Governance costs

	Restricted £	Unrestricted £	2024 £	2023 £
Governance costs heading 1	-	887	887	540
Bank charges	-	58	58	68
Depreciation	-	515	515	604
	<u>-</u>	<u>1,460</u>	<u>1,460</u>	<u>1,212</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

5 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

6 Employees

The average monthly number of employees during the year was:

	2024	2023
	Number	Number
	3	4
	<u> </u>	<u> </u>
Employment costs	2024	2023
	£	£
Wages and salaries	35,211	58,542
Other pension costs	598	651
	<u> </u>	<u> </u>
	<u>35,809</u>	<u>59,193</u>

There were no employees whose annual remuneration was more than £60,000.

Remuneration of key management personnel

The remuneration of key management personnel was as follows:

7 Tangible fixed assets

	Fixtures and fittings
	£
Cost	
At 1 April 2023	4,607
Additions	250
	<u> </u>
At 31 March 2024	4,857
	<u> </u>
Depreciation and impairment	
At 1 April 2023	2,796
Depreciation charged in the year	515
	<u> </u>
At 31 March 2024	3,311
	<u> </u>
Carrying amount	
At 31 March 2024	1,546
	<u> </u>
At 31 March 2023	1,811
	<u> </u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

8 Debtors		2024	2023
		£	£
Amounts falling due within one year:			
Trade debtors		10,000	-
Other debtors		-	1,307
		<u>10,000</u>	<u>1,307</u>
		<u><u>10,000</u></u>	<u><u>1,307</u></u>
9 Creditors: amounts falling due within one year		2024	2023
		£	£
Other taxation and social security		387	729
Other creditors		-	1,594
Accruals and deferred income		1,205	1,786
		<u>1,592</u>	<u>4,109</u>
		<u><u>1,592</u></u>	<u><u>4,109</u></u>
10 Retirement benefit schemes		2024	2023
		£	£
Defined contribution schemes			
Charge to profit or loss in respect of defined contribution schemes		598	651
		<u>598</u>	<u>651</u>
		<u><u>598</u></u>	<u><u>651</u></u>

The charity operates a defined contribution pension scheme for all qualifying employees. The assets of the scheme are held separately from those of the charity in an independently administered fund.

11 Restricted funds

The restricted funds of the charity comprise the unexpended balances of donations and grants held on trust subject to specific conditions by donors as to how they may be used.

	At 1 April	Incoming	Resources	At 31 March
	2023	resources	expended	2024
	£	£	£	£
	12,728	52,000	(36,565)	28,163
	<u>12,728</u>	<u>52,000</u>	<u>(36,565)</u>	<u>28,163</u>
Previous year:	At 1 April	Incoming	Resources	At 31 March
	2022	resources	expended	2023
	£	£	£	£
	36,957	38,239	(62,468)	12,728
	<u>36,957</u>	<u>38,239</u>	<u>(62,468)</u>	<u>12,728</u>
	<u><u>36,957</u></u>	<u><u>38,239</u></u>	<u><u>(62,468)</u></u>	<u><u>12,728</u></u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2024

12 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used. These include designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 April 2023	Incoming resources	Resources expended	At 31 March 2024
	£	£	£	£
General funds	19,272	9,700	(12,215)	16,757
	<u> </u>	<u> </u>	<u> </u>	<u> </u>
Previous year:	At 1 April 2022	Incoming resources	Resources expended	At 31 March 2023
	£	£	£	£
General funds	18,476	10,985	(10,189)	19,272
	<u> </u>	<u> </u>	<u> </u>	<u> </u>

13 Related party transactions

There were no disclosable related party transactions during the year (2023 - none).












NIRDP Accounts for signing


Final Audit Report

2024-12-23


Created:	2024-12-23
By:	June Stevenson (June@mtsaccountants.com)
Status:	Signed
Transaction ID:	CBJCHBCAABAAPysW8rkkEC3WmF3RsNGFALQoC0EKmAOr

"NIRDP Accounts for signing" History

-  Document created by June Stevenson (June@mtsaccountants.com)
2024-12-23 - 09:27:53 GMT
-  Document emailed to paula@mtsaccountants.com for signature
2024-12-23 - 09:30:47 GMT
-  Email viewed by paula@mtsaccountants.com
2024-12-23 - 09:31:50 GMT
-  Signer paula@mtsaccountants.com entered name at signing as Paula Armstrong
2024-12-23 - 09:32:31 GMT
-  Document e-signed by Paula Armstrong (paula@mtsaccountants.com)
Signature Date: 2024-12-23 - 09:32:33 GMT - Time Source: server
-  Document emailed to chair@nirdp.org.uk for signature
2024-12-23 - 09:32:34 GMT
-  Email viewed by chair@nirdp.org.uk
2024-12-23 - 10:12:10 GMT
-  Signer chair@nirdp.org.uk entered name at signing as Sarah Callaghan
2024-12-23 - 10:13:12 GMT
-  Document e-signed by Sarah Callaghan (chair@nirdp.org.uk)
Signature Date: 2024-12-23 - 10:13:14 GMT - Time Source: server
-  Document emailed to amoloan@nirdp.org.uk for signature
2024-12-23 - 10:13:16 GMT
-  Email viewed by amoloan@nirdp.org.uk
2024-12-23 - 22:25:25 GMT

 Signer amoloan@nirdp.org.uk entered name at signing as Anne-Marie O'Loan
2024-12-23 - 22:28:14 GMT

 Document e-signed by Anne-Marie O'Loan (amoloan@nirdp.org.uk)
Signature Date: 2024-12-23 - 22:28:16 GMT - Time Source: server

 Agreement completed.
2024-12-23 - 22:28:16 GMT

Northern Ireland Rare Disease Partnership

Northern Ireland - Charity number 105261

Accounts

Charity Registration No. 105261

Company Registration No. NI611153 (Northern Ireland)

**NORTHERN IRELAND RARE DISEASE PARTNERSHIP
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	C Donnelly S Callaghan A O'Loan J Wright J McEvoy C McKenna Dr N Chaudhuri	(Appointed 10 July 2022) (Appointed 10 July 2022) (Appointed 10 July 2022) (Appointed 10 June 2022) (Appointed 21 February 2023)
Charity number	105261	
Company number	NI611153	
Registered office	Guardian Chartered Accountants 2 William Street Newtownards BT23 4AH	
Independent examiner	MTS Prior McMahon 104-108 Frances Street Newtownards Down BT23 7DY	

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

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Statement of financial activities	2
Balance sheet	3
Notes to the financial statements	4 - 9

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF NORTHERN IRELAND RARE DISEASE PARTNERSHIP

I report to the trustees on my examination of the financial statements of NORTHERN IRELAND RARE DISEASE PARTNERSHIP (the charity) for the year ended 31 March 2023.

Responsibilities and basis of report

As the trustees of the charity (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 (the 2006 Act).

Having satisfied myself that the charity is not subject to audit under company law, and is eligible for independent examination, it is my responsibility to:

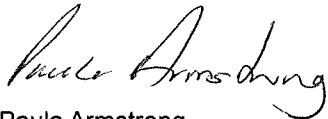
- examine the accounts under section 65 of the Charities Act
- follow the procedures laid down in the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act
- state whether particular matters have come to my attention.

Independent examiner's statement

I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in accordance with the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act. The examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1 accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
- 4 the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the financial statements to be reached.



Paula Armstrong
For and on behalf of MTS Prior McMahon

Chartered Accountants
104-108 Frances Street
Newtownards
Down
BT23 7DY

Dated: 29 November 2023

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2023

	Notes	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Total 2022 £
Income from:					
Donations and legacies	2	10,985	38,239	49,224	68,696
Investments	3	-	-	-	18
Total income		<u>10,985</u>	<u>38,239</u>	<u>49,224</u>	<u>68,714</u>
Expenditure on:					
Charitable activities	4	10,189	62,468	72,657	37,839
Other	8	-	-	-	611
Total resources expended		<u>10,189</u>	<u>62,468</u>	<u>72,657</u>	<u>38,450</u>
Net income/(expenditure) for the year/ Net movement in funds		796	(24,229)	(23,433)	30,264
Fund balances at 1 April 2022		<u>18,476</u>	<u>36,957</u>	<u>55,433</u>	<u>25,169</u>
Fund balances at 31 March 2023		<u><u>19,272</u></u>	<u><u>12,728</u></u>	<u><u>32,000</u></u>	<u><u>55,433</u></u>

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

BALANCE SHEET

AS AT 31 MARCH 2023

	Notes	2023 £	£	2022 £	£
Fixed assets					
Tangible assets	9		1,811		1,158
Current assets					
Debtors	10	1,307		197	
Cash at bank and in hand		32,991		55,845	
		<u>34,298</u>		<u>56,042</u>	
Creditors: amounts falling due within one year	11	<u>(4,109)</u>		<u>(1,767)</u>	
Net current assets			30,189		54,275
Total assets less current liabilities			<u>32,000</u>		<u>55,433</u>
Income funds					
Restricted funds			12,728		36,957
Unrestricted funds			19,272		18,476
			<u>32,000</u>		<u>55,433</u>

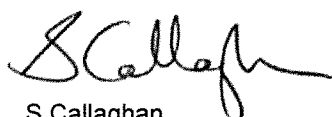
The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 March 2023.

The trustees acknowledge their responsibilities for ensuring that the charity keeps accounting records which comply with section 386 of the Act and for preparing financial statements which give a true and fair view of the state of affairs of the company as at the end of the financial year and of its incoming resources and application of resources, including its income and expenditure, for the financial year in accordance with the requirements of sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the company.

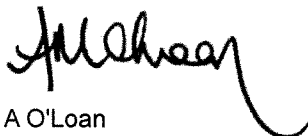
The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the Trustees on 29 November 2023



S Callaghan
Trustee



A O'Loan
Trustee

Company Registration No. NI611153

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

Charity information

NORTHERN IRELAND RARE DISEASE PARTNERSHIP is a private company limited by guarantee incorporated in Northern Ireland. The registered office is Guardian Chartered Accountants, 2 William Street, Newtownards, BT23 4AH.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's articles of association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2016). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

(Continued)

1.5 Resources expended

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates;

- Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

- Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees and costs linked to the strategic management of the charity.

All costs are allocated between the expenditure categories of the SOFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, others are apportioned on an appropriate basis.

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	25% reducing balance
-----------------------	----------------------

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income/(expenditure) for the year.

1.7 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.8 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.9 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

(Continued)

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.10 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

1.11 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

2 Donations and legacies

	Unrestricted funds	Restricted funds	Total	Total
	2023	2023	2023	2022
	£	£	£	£
Donations and gifts	10,985	-	10,985	6,671
Grants	-	38,239	38,239	62,025
	<u>10,985</u>	<u>38,239</u>	<u>49,224</u>	<u>68,696</u>
For the year ended 31 March 2022	<u>6,671</u>	<u>62,025</u>		<u>68,696</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

2 Donations and legacies

(Continued)

Donations and gifts

Donations	10,943	-	10,943	6,671
Other	42	-	42	-
	<u>10,985</u>	<u>-</u>	<u>10,985</u>	<u>6,671</u>

3 Investments

	Unrestricted funds	Total
	2023 £	2022 £
Interest receivable	-	18
	<u>-</u>	<u>18</u>

4 Charitable activities

	2023 £	2022 £
Staff costs	59,193	30,840
Staff and board training	1,222	-
Forum costs and room hire	-	99
Subscriptions	65	70
Insurance	96	96
Printing, postage and stationery	803	120
Advertising and promotional costs	853	1,964
Telephone	172	168
Computer and internet costs	2,514	2,708
Motor and travel expenses	2,127	551
Consultancy	3,125	-
Event expenses	886	-
General expenses	389	229
	<u>71,445</u>	<u>36,845</u>
Share of governance costs (see note 5)	1,212	994
	<u>72,657</u>	<u>37,839</u>
Analysis by fund		
Unrestricted funds	10,189	3,621
Restricted funds	62,468	34,218
	<u>72,657</u>	<u>37,839</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

5 Governance costs

	Restricted £	Unrestricted £	2023 £	2022 £
Governance costs heading 1	-	540	540	474
Bank charges	-	68	68	134
Depreciation	-	604	604	386
	<u>-</u>	<u>1,212</u>	<u>1,212</u>	<u>994</u>

6 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

7 Employees

Number of employees

The average monthly number of employees during the year was:

	2023 Number	2022 Number
	4	2
	<u>4</u>	<u>2</u>

Employment costs

	2023 £	2022 £
Wages and salaries	58,542	30,465
Other pension costs	651	375
	<u>59,193</u>	<u>30,840</u>

8 Other

	Unrestricted funds	Total
	2023 £	2022 £
Net loss on disposal of tangible fixed assets	-	611
	<u>-</u>	<u>611</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

9 Tangible fixed assets

	Fixtures and fittings £
Cost	
At 1 April 2022	3,350
Additions	1,257
	<hr/>
At 31 March 2023	4,607
	<hr/>
Depreciation and impairment	
At 1 April 2022	2,192
Depreciation charged in the year	604
	<hr/>
At 31 March 2023	2,796
	<hr/>
Carrying amount	
At 31 March 2023	1,811
	<hr/> <hr/>
At 31 March 2022	1,158
	<hr/> <hr/>

10 Debtors

	2023 £	2022 £
Amounts falling due within one year:		
Other debtors	1,307	197
	<hr/>	<hr/>

11 Creditors: amounts falling due within one year

	2023 £	2022 £
Other taxation and social security	729	880
Other creditors	1,594	377
Accruals and deferred income	1,786	510
	<hr/>	<hr/>
	4,109	1,767
	<hr/> <hr/>	<hr/> <hr/>

12 Related party transactions

There were no disclosable related party transactions during the year (2022 - none).

Northern Ireland Rare Disease Partnership

Northern Ireland - Charity number 105261

Annual report

Charity Registration No. 105261

Company Registration No. NI611153 (Northern Ireland)

**NORTHERN IRELAND RARE DISEASE PARTNERSHIP
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	C Donnelly S Callaghan A O'Loan J Wright J McEvoy C McKenna Dr N Chaudhuri	(Appointed 10 July 2022) (Appointed 10 July 2022) (Appointed 10 July 2022) (Appointed 10 June 2022) (Appointed 21 February 2023)
Charity number	105261	
Company number	NI611153	
Registered office	Guardian Chartered Accountants 2 William Street Newtownards BT23 4AH	
Independent examiner	MTS Prior McMahon 104-108 Frances Street Newtownards Down BT23 7DY	

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

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Statement of financial activities	2
Balance sheet	3
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NORTHERN IRELAND RARE DISEASE PARTNERSHIP

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF NORTHERN IRELAND RARE DISEASE PARTNERSHIP

I report to the trustees on my examination of the financial statements of NORTHERN IRELAND RARE DISEASE PARTNERSHIP (the charity) for the year ended 31 March 2023.

Responsibilities and basis of report

As the trustees of the charity (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 (the 2006 Act).

Having satisfied myself that the charity is not subject to audit under company law, and is eligible for independent examination, it is my responsibility to:

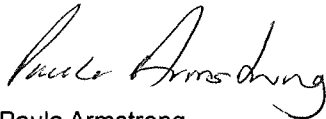
- examine the accounts under section 65 of the Charities Act
- follow the procedures laid down in the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act
- state whether particular matters have come to my attention.

Independent examiner's statement

I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in accordance with the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act. The examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1 accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
- 4 the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the financial statements to be reached.



Paula Armstrong
For and on behalf of MTS Prior McMahon

Chartered Accountants
104-108 Frances Street
Newtownards
Down
BT23 7DY

Dated: 29 November 2023

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2023

	Notes	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Total 2022 £
Income from:					
Donations and legacies	2	10,985	38,239	49,224	68,696
Investments	3	-	-	-	18
Total income		<u>10,985</u>	<u>38,239</u>	<u>49,224</u>	<u>68,714</u>
Expenditure on:					
Charitable activities	4	10,189	62,468	72,657	37,839
Other	8	-	-	-	611
Total resources expended		<u>10,189</u>	<u>62,468</u>	<u>72,657</u>	<u>38,450</u>
Net income/(expenditure) for the year/ Net movement in funds		796	(24,229)	(23,433)	30,264
Fund balances at 1 April 2022		<u>18,476</u>	<u>36,957</u>	<u>55,433</u>	<u>25,169</u>
Fund balances at 31 March 2023		<u><u>19,272</u></u>	<u><u>12,728</u></u>	<u><u>32,000</u></u>	<u><u>55,433</u></u>

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

BALANCE SHEET

AS AT 31 MARCH 2023

	Notes	2023 £	£	2022 £	£
Fixed assets					
Tangible assets	9		1,811		1,158
Current assets					
Debtors	10	1,307		197	
Cash at bank and in hand		32,991		55,845	
		<u>34,298</u>		<u>56,042</u>	
Creditors: amounts falling due within one year	11	<u>(4,109)</u>		<u>(1,767)</u>	
Net current assets			30,189		54,275
Total assets less current liabilities			<u>32,000</u>		<u>55,433</u>
Income funds					
Restricted funds			12,728		36,957
Unrestricted funds			19,272		18,476
			<u>32,000</u>		<u>55,433</u>

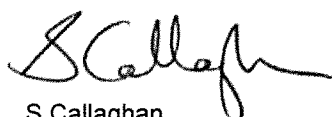
The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 March 2023.

The trustees acknowledge their responsibilities for ensuring that the charity keeps accounting records which comply with section 386 of the Act and for preparing financial statements which give a true and fair view of the state of affairs of the company as at the end of the financial year and of its incoming resources and application of resources, including its income and expenditure, for the financial year in accordance with the requirements of sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the company.

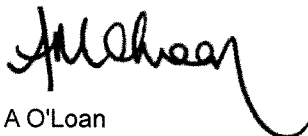
The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the Trustees on 29 November 2023



S Callaghan
Trustee



A O'Loan
Trustee

Company Registration No. NI611153

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

Charity information

NORTHERN IRELAND RARE DISEASE PARTNERSHIP is a private company limited by guarantee incorporated in Northern Ireland. The registered office is Guardian Chartered Accountants, 2 William Street, Newtownards, BT23 4AH.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's articles of association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2016). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

(Continued)

1.5 Resources expended

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates;

- Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

- Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees and costs linked to the strategic management of the charity.

All costs are allocated between the expenditure categories of the SOFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, others are apportioned on an appropriate basis.

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	25% reducing balance
-----------------------	----------------------

The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income/(expenditure) for the year.

1.7 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.8 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.9 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

(Continued)

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.10 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

1.11 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

2 Donations and legacies

	Unrestricted funds	Restricted funds	Total	Total
	2023	2023	2023	2022
	£	£	£	£
Donations and gifts	10,985	-	10,985	6,671
Grants	-	38,239	38,239	62,025
	<u>10,985</u>	<u>38,239</u>	<u>49,224</u>	<u>68,696</u>
For the year ended 31 March 2022	<u>6,671</u>	<u>62,025</u>		<u>68,696</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

2 Donations and legacies

(Continued)

Donations and gifts

Donations	10,943	-	10,943	6,671
Other	42	-	42	-
	<u>10,985</u>	<u>-</u>	<u>10,985</u>	<u>6,671</u>

3 Investments

	Unrestricted funds	Total
	2023 £	2022 £
Interest receivable	-	18
	<u>-</u>	<u>18</u>

4 Charitable activities

	2023 £	2022 £
Staff costs	59,193	30,840
Staff and board training	1,222	-
Forum costs and room hire	-	99
Subscriptions	65	70
Insurance	96	96
Printing, postage and stationery	803	120
Advertising and promotional costs	853	1,964
Telephone	172	168
Computer and internet costs	2,514	2,708
Motor and travel expenses	2,127	551
Consultancy	3,125	-
Event expenses	886	-
General expenses	389	229
	<u>71,445</u>	<u>36,845</u>
Share of governance costs (see note 5)	1,212	994
	<u>72,657</u>	<u>37,839</u>
Analysis by fund		
Unrestricted funds	10,189	3,621
Restricted funds	62,468	34,218
	<u>72,657</u>	<u>37,839</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

5 Governance costs

	Restricted £	Unrestricted £	2023 £	2022 £
Governance costs heading 1	-	540	540	474
Bank charges	-	68	68	134
Depreciation	-	604	604	386
	<u>-</u>	<u>1,212</u>	<u>1,212</u>	<u>994</u>

6 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

7 Employees

Number of employees

The average monthly number of employees during the year was:

	2023 Number	2022 Number
	4	2
	<u>4</u>	<u>2</u>

Employment costs

	2023 £	2022 £
Wages and salaries	58,542	30,465
Other pension costs	651	375
	<u>59,193</u>	<u>30,840</u>

8 Other

	Unrestricted funds	Total
	2023 £	2022 £
Net loss on disposal of tangible fixed assets	-	611
	<u>-</u>	<u>611</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

9 Tangible fixed assets	Fixtures and fittings
	£
Cost	
At 1 April 2022	3,350
Additions	1,257
	<hr/>
At 31 March 2023	4,607
	<hr/>
Depreciation and impairment	
At 1 April 2022	2,192
Depreciation charged in the year	604
	<hr/>
At 31 March 2023	2,796
	<hr/>
Carrying amount	
At 31 March 2023	1,811
	<hr/> <hr/>
At 31 March 2022	1,158
	<hr/> <hr/>

10 Debtors	2023	2022
	£	£
Amounts falling due within one year:		
Other debtors	1,307	197
	<hr/> <hr/>	<hr/> <hr/>

11 Creditors: amounts falling due within one year	2023	2022
	£	£
Other taxation and social security	729	880
Other creditors	1,594	377
Accruals and deferred income	1,786	510
	<hr/>	<hr/>
	4,109	1,767
	<hr/> <hr/>	<hr/> <hr/>

12 Related party transactions

There were no disclosable related party transactions during the year (2022 - none).

Northern Ireland Rare Disease Partnership

Northern Ireland - Charity number 105261

Annual return

Charity Registration No. 105261

Company Registration No. NI611153 (Northern Ireland)

**NORTHERN IRELAND RARE DISEASE PARTNERSHIP
ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2023**

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	C Donnelly S Callaghan A O'Loan J Wright J McEvoy C McKenna Dr N Chaudhuri	(Appointed 10 July 2022) (Appointed 10 July 2022) (Appointed 10 July 2022) (Appointed 10 June 2022) (Appointed 21 February 2023)
Charity number	105261	
Company number	NI611153	
Registered office	Guardian Chartered Accountants 2 William Street Newtownards BT23 4AH	
Independent examiner	MTS Prior McMahon 104-108 Frances Street Newtownards Down BT23 7DY	

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

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NORTHERN IRELAND RARE DISEASE PARTNERSHIP

INDEPENDENT EXAMINER'S REPORT

TO THE TRUSTEES OF NORTHERN IRELAND RARE DISEASE PARTNERSHIP

I report to the trustees on my examination of the financial statements of NORTHERN IRELAND RARE DISEASE PARTNERSHIP (the charity) for the year ended 31 March 2023.

Responsibilities and basis of report

As the trustees of the charity (and also its directors for the purposes of company law) you are responsible for the preparation of the financial statements in accordance with the requirements of the Companies Act 2006 (the 2006 Act).

Having satisfied myself that the charity is not subject to audit under company law, and is eligible for independent examination, it is my responsibility to:

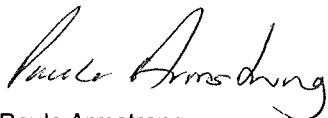
- examine the accounts under section 65 of the Charities Act
- follow the procedures laid down in the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act
- state whether particular matters have come to my attention.

Independent examiner's statement

I have examined your charity accounts as required under section 65 of the Charities Act and my examination was carried out in accordance with the general Directions given by the Charity Commission for Northern Ireland under section 65(9)(b) of the Charities Act. The examination included a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also included consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as charity trustees concerning any such matters. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1 accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
- 4 the financial statements have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the financial statements to be reached.



Paula Armstrong
For and on behalf of MTS Prior McMahon

Chartered Accountants
104-108 Frances Street
Newtownards
Down
BT23 7DY

Dated: 29 November 2023

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31 MARCH 2023

	Notes	Unrestricted funds 2023 £	Restricted funds 2023 £	Total 2023 £	Total 2022 £
Income from:					
Donations and legacies	2	10,985	38,239	49,224	68,696
Investments	3	-	-	-	18
Total income		<u>10,985</u>	<u>38,239</u>	<u>49,224</u>	<u>68,714</u>
Expenditure on:					
Charitable activities	4	10,189	62,468	72,657	37,839
Other	8	-	-	-	611
Total resources expended		<u>10,189</u>	<u>62,468</u>	<u>72,657</u>	<u>38,450</u>
Net income/(expenditure) for the year/ Net movement in funds		796	(24,229)	(23,433)	30,264
Fund balances at 1 April 2022		<u>18,476</u>	<u>36,957</u>	<u>55,433</u>	<u>25,169</u>
Fund balances at 31 March 2023		<u><u>19,272</u></u>	<u><u>12,728</u></u>	<u><u>32,000</u></u>	<u><u>55,433</u></u>

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

BALANCE SHEET

AS AT 31 MARCH 2023

	Notes	2023 £	£	2022 £	£
Fixed assets					
Tangible assets	9		1,811		1,158
Current assets					
Debtors	10	1,307		197	
Cash at bank and in hand		32,991		55,845	
		<u>34,298</u>		<u>56,042</u>	
Creditors: amounts falling due within one year	11	<u>(4,109)</u>		<u>(1,767)</u>	
Net current assets			30,189		54,275
Total assets less current liabilities			<u>32,000</u>		<u>55,433</u>
Income funds					
Restricted funds			12,728		36,957
Unrestricted funds			19,272		18,476
			<u>32,000</u>		<u>55,433</u>

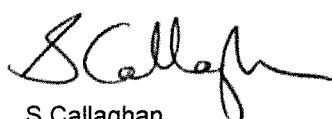
The company is entitled to the exemption from the audit requirement contained in section 477 of the Companies Act 2006, for the year ended 31 March 2023.

The trustees acknowledge their responsibilities for ensuring that the charity keeps accounting records which comply with section 386 of the Act and for preparing financial statements which give a true and fair view of the state of affairs of the company as at the end of the financial year and of its incoming resources and application of resources, including its income and expenditure, for the financial year in accordance with the requirements of sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the company.

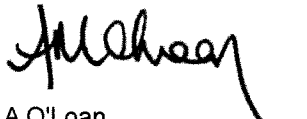
The members have not required the company to obtain an audit of its financial statements for the year in question in accordance with section 476.

These financial statements have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

The financial statements were approved by the Trustees on 29 November 2023



S Callaghan
Trustee



A O'Loan
Trustee

Company Registration No. NI611153

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

Charity information

NORTHERN IRELAND RARE DISEASE PARTNERSHIP is a private company limited by guarantee incorporated in Northern Ireland. The registered office is Guardian Chartered Accountants, 2 William Street, Newtownards, BT23 4AH.

1.1 Accounting convention

The financial statements have been prepared in accordance with the charity's articles of association, the Companies Act 2006 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (as amended for accounting periods commencing from 1 January 2016). The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities applying FRS 102 Update Bulletin 1 not to prepare a Statement of Cash Flows.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value. The principal accounting policies adopted are set out below.

1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives unless the funds have been designated for other purposes.

Restricted funds are subject to specific conditions by donors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

1.4 Incoming resources

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

(Continued)

1.5 Resources expended

Expenditure is recognised on an accrual basis as a liability is incurred. Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates;

- Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

- Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees and costs linked to the strategic management of the charity.

All costs are allocated between the expenditure categories of the SOFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are allocated directly, others are apportioned on an appropriate basis.

1.6 Tangible fixed assets

Tangible fixed assets are initially measured at cost and subsequently measured at cost or valuation, net of depreciation and any impairment losses.

Depreciation is recognised so as to write off the cost or valuation of assets less their residual values over their useful lives on the following bases:

Fixtures and fittings	25% reducing balance
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The gain or loss arising on the disposal of an asset is determined as the difference between the sale proceeds and the carrying value of the asset, and is recognised in net income/(expenditure) for the year.

1.7 Impairment of fixed assets

At each reporting end date, the charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

1.8 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

1.9 Financial instruments

The charity has elected to apply the provisions of Section 11 'Basic Financial Instruments' and Section 12 'Other Financial Instruments Issues' of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the charity's balance sheet when the charity becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

1 Accounting policies

(Continued)

Basic financial liabilities

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

Derecognition of financial liabilities

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

1.10 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

1.11 Retirement benefits

Payments to defined contribution retirement benefit schemes are charged as an expense as they fall due.

2 Donations and legacies

	Unrestricted funds	Restricted funds	Total	Total
	2023	2023	2023	2022
	£	£	£	£
Donations and gifts	10,985	-	10,985	6,671
Grants	-	38,239	38,239	62,025
	<u>10,985</u>	<u>38,239</u>	<u>49,224</u>	<u>68,696</u>
For the year ended 31 March 2022	<u>6,671</u>	<u>62,025</u>		<u>68,696</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

2 Donations and legacies

(Continued)

Donations and gifts

Donations	10,943	-	10,943	6,671
Other	42	-	42	-
	<u>10,985</u>	<u>-</u>	<u>10,985</u>	<u>6,671</u>

3 Investments

	Unrestricted funds	Total
	2023 £	2022 £
Interest receivable	-	18
	<u>-</u>	<u>18</u>

4 Charitable activities

	2023 £	2022 £
Staff costs	59,193	30,840
Staff and board training	1,222	-
Forum costs and room hire	-	99
Subscriptions	65	70
Insurance	96	96
Printing, postage and stationery	803	120
Advertising and promotional costs	853	1,964
Telephone	172	168
Computer and internet costs	2,514	2,708
Motor and travel expenses	2,127	551
Consultancy	3,125	-
Event expenses	886	-
General expenses	389	229
	<u>71,445</u>	<u>36,845</u>
Share of governance costs (see note 5)	1,212	994
	<u>72,657</u>	<u>37,839</u>
Analysis by fund		
Unrestricted funds	10,189	3,621
Restricted funds	62,468	34,218
	<u>72,657</u>	<u>37,839</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2023

5 Governance costs

	Restricted £	Unrestricted £	2023 £	2022 £
Governance costs heading 1	-	540	540	474
Bank charges	-	68	68	134
Depreciation	-	604	604	386
	<u>-</u>	<u>1,212</u>	<u>1,212</u>	<u>994</u>

6 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

7 Employees

Number of employees

The average monthly number of employees during the year was:

	2023 Number	2022 Number
	4	2
	<u>4</u>	<u>2</u>

Employment costs

	2023 £	2022 £
Wages and salaries	58,542	30,465
Other pension costs	651	375
	<u>59,193</u>	<u>30,840</u>

8 Other

	Unrestricted funds	Total
	2023 £	2022 £
Net loss on disposal of tangible fixed assets	-	611
	<u>-</u>	<u>611</u>

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE YEAR ENDED 31 MARCH 2023

9 Tangible fixed assets		Fixtures and fittings
		£
Cost		
At 1 April 2022		3,350
Additions		1,257
		<u>4,607</u>
At 31 March 2023		4,607
Depreciation and impairment		
At 1 April 2022		2,192
Depreciation charged in the year		604
		<u>2,796</u>
At 31 March 2023		2,796
Carrying amount		
At 31 March 2023		1,811
		<u>1,158</u>
At 31 March 2022		<u>1,158</u>

10 Debtors		2023	2022
Amounts falling due within one year:		£	£
Other debtors		1,307	197
		<u>1,307</u>	<u>197</u>

11 Creditors: amounts falling due within one year		2023	2022
		£	£
Other taxation and social security		729	880
Other creditors		1,594	377
Accruals and deferred income		1,786	510
		<u>4,109</u>	<u>1,767</u>

12 Related party transactions

There were no disclosable related party transactions during the year (2022 - none).